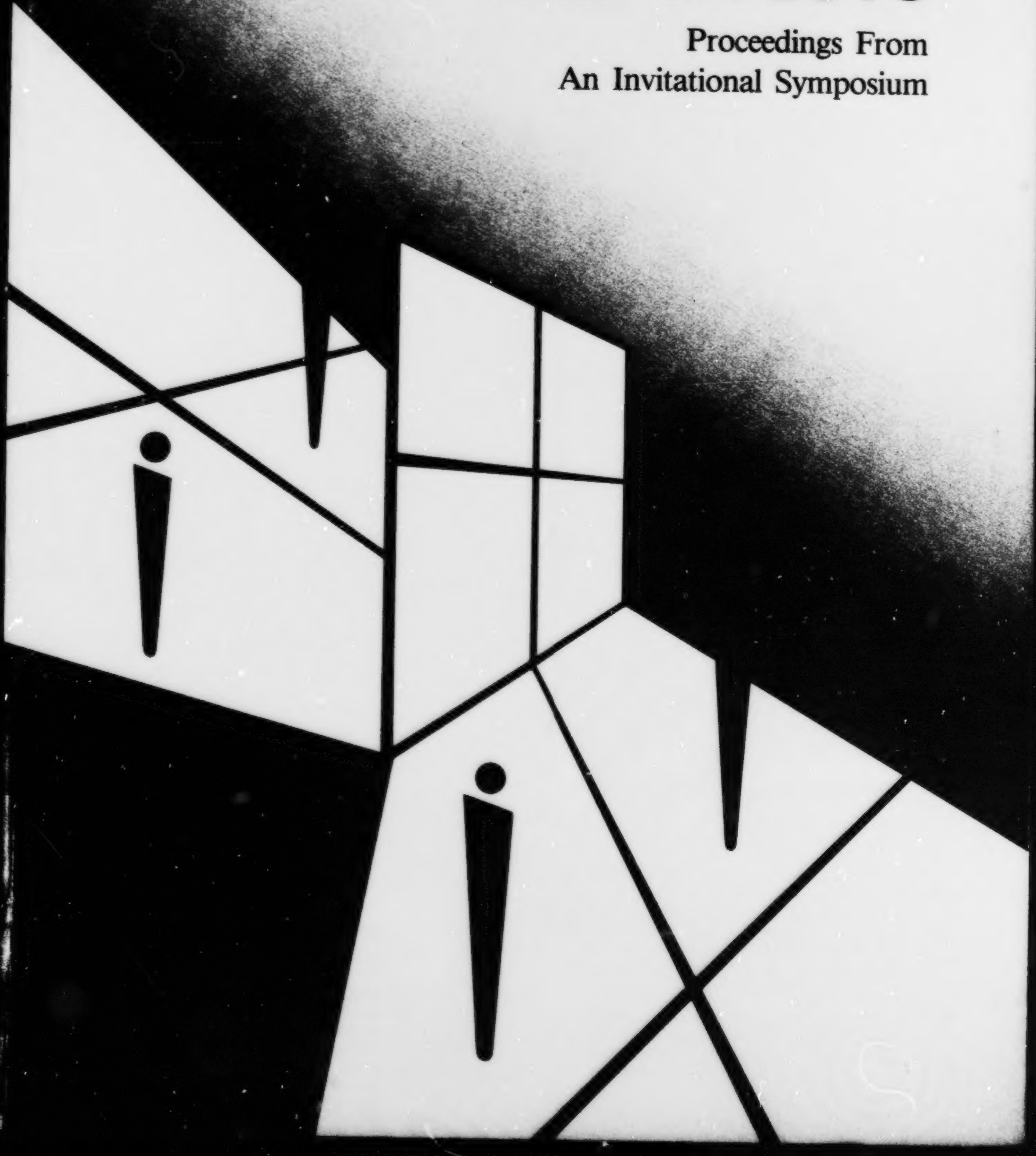
DEINSTITUTIONALIZATION
COSTS AND EFFECTS

Proceedings From
An Invitational Symposium



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The Canadian Council on Social Development

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Founded in 1920, the Canadian Council on Social Development (CCSD) is a national non-governmental, non-profit organization. Through independent research, policy analysis, community consultation and information sharing, the CCSD provides a forum for citizen participation in the formulation of enlightened social policies.

The CCSD is the only national organization whose mandate and involvement embrace all aspects of social development and social policy. Since its beginning, the Council has been actively involved in the evaluation of existing programs, the identification of essential improvements, and the promotion of needed developments. It has been a positive, non-partisan advocate of social measures such as universal inoculation, pensions, unemployment assistance, workmen's compensation, medicare, legal aid, daycare, and social and cooperative housing. The Council played an active role in the development of the Canada Assistance Plan and the Child Tax Credit, and has been a promoter of the Guaranteed Annual Income concept.

The CCSD is not a "think tank". It **is** the only national social research, advocacy and policy organization with an open public membership. CCSD's analyses, opinions, research and information reflect not only highly professional technical work but also the active analysis and shared experience of its broadly representative membership.

The Council's diverse membership includes concerned individuals as well as representatives from business, labour, government, public and private service organizations, voluntary associations and institutions. An annual meeting of the membership reviews the year's program and financial activities. Council activities are directed by a voluntary 39-member Board of Governors. Board members are formally elected at the annual meeting for terms of one, two and three years.

The CCSD is a major publisher in the field of social development. Publications include: research reports and policy briefs; **Perception**, a bi-monthly, bilingual magazine of social comment and analysis; **Overview**, a quarterly newsletter reviewing current national developments.

National headquarters of the Canadian Council on Social Development are located at 55 Parkdale Avenue, Ottawa, Ontario, K1Y 4G1. Tel: (613) 728-1865. Membership information is provided on the inside back cover.

Le Conseil canadien de Développement social

QU'EST-CE QUE LE CCDS?

Le Conseil canadien de Développement social (CCDS) est une organisation nationale privée à but non lucratif fondée en 1920. Le Conseil encourage les citoyens à participer à l'élaboration de politiques sociales éclairées par voie de recherches indépendantes, d'analyses de politiques, de consultations communautaires et de dissémination d'informations.

Le CCDS est le seul organisme national dont le mandat et le secteur d'activités recouvrent tous les aspects du développement social et de la politique sociale. Depuis ses débuts, le Conseil participe activement à l'évaluation des programmes courants, à l'identification des améliorations jugées nécessaires et à la promotion des solutions qui s'imposent. Le Conseil s'est fait le porte-parole positif et non-partisan de mesures sociales telles que: les vaccins universels, les pensions, l'aide aux chômeurs, les indemnisations aux travailleurs, l'assurance-santé, l'aide juridique, les garderies, ainsi que le logement social et coopératif. Le Conseil a participé activement à l'élaboration du Régime d'assistance publique du Canada et du crédit fiscal pour enfants; il a de plus appuyé le concept du revenu annuel garanti.

Le CCDS n'est pas un "laboratoire d'idées" dans une tour d'ivoire. Il s'agit cependant du seul organisme national de recherche, de politiques sociales et de démarchage qui recrute ouvertement ses membres parmi le public. Les analyses, opinions, recherches et l'information produites par le Conseil découlent non seulement d'un travail technique hautement professionnel mais proviennent aussi de la réflection et de l'expérience partagées de membres largement représentatifs.

Parmi ces derniers, l'on retrouve des individus intéressés, ainsi que des représentants d'entreprises, de syndicats, de gouvernements, d'organismes publics et privés assurant la prestation de services, ainsi que d'associations et d'institutions bénévoles. Les membres du Conseil se réunissent annuellement afin de revoir le programme de l'année, ainsi que les activités financières du CCDS. Un bureau des gouverneurs composé de 39 membres bénévoles dirige les activités du Conseil. Les gouverneurs sont élus officiellement lors de la réunion annuelle pour un mandat d'une, deux ou trois année(s).

Le CCDS publie beaucoup dans le secteur du développement social. Ses publications comprennent entre autres: des rapports de recherches et des mémoires politiques; **Perception**, un magazine bilingue et bimensuel d'analyse et de critique sociale; **Perspective**, un bulletin trimestriel sur l'actualité nationale.

Les bureaux du Conseil canadien de Développement social sont situés au 55, avenue Parkdale, Ottawa, Ontario, K1Y 4G1. N° de téléphone: (613) 728-1865. On retrouvera des détails complémentaires sur l'adhésion à l'endos de la couverture arrière.

DEINSTITUTIONALIZATION:
COSTS AND EFFECTS

PROCEEDINGS FROM AN INVITATIONAL SYMPOSIUM
TORONTO
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Canadian Council on Social Development
Ottawa

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FOREWORD

The Canadian Council on Social Development has been interested in promoting support services to disabled persons for many years. We were very pleased to be invited by Health and Welfare Canada to co-ordinate a feasibility study on the cost-effectiveness of deinstitutionalization in Canada.

One of several results of the feasibility study is the publication of these papers, presented at an Invitational Symposium on "Deinstitutionalization: Costs and Effects".

The symposium was planned under the guidance of a working group to whom we extend our appreciation:

Carol Stubbs, "On Our Own"
Bruce Kappel, Canadian Association for Community Living
Peter Lawless, Health and Welfare Canada
Leslie Laframboise, "People First"
Harry MacKay, Canadian Council on Social Development
Rick Miles and Henry Enns, Coalition of Provincial Organizations of the Handicapped
Gordon Morwood, Canadian Mental Health Association
Maureen Vasey, Canadian Rehabilitation Council for the Disabled

Fortunately, the members immediately agreed to endorse the principle of normalization (living as normal a life as possible) to be the fundamental premise of deinstitutionalization. Members also readily agreed that current service levels and availability are inadequate, and that more support is needed for increased opportunities for disabled persons. Attention then turned to the gaps in information which prompted this invitational symposium.

We thank the Ministry of Communications of the Government of Québec, and particularly Lorette Robillard from the Office des Personnes handicapées du Québec for translating the papers into French. Our thanks also go to Health and Welfare Canada for supporting the distribution of this publication to disabled persons across Canada.

After reviewing the literature and hearing these papers, and after serious reflection, the Council's Board of Governors concluded there is need for a profile of disabled persons in Canada and a pilot study into the cost-effectiveness of deinstitutionalization in Canada.

We now urge governments, along with disabled persons, to begin substantial and long-term research into the quality of life of disabled persons and its cost.

Terrance M. Hunsley
Executive Director

November, 1985.

INTRODUCTION

In 1983, Health and Welfare Canada commissioned the Canadian Council on Social Development (CCSD) to establish the feasibility of undertaking a national study of the cost-effectiveness of deinstitutionalization in Canada, as recommended in the **Obstacles** Report (Recommendation 103).

Along with a working group of consumers and professional organizations of disabled persons, the CCSD co-ordinated the production of a literature review (1), published the papers (2) presented at an invitational symposium held to gather and share new information, and wrote a final report (3) that concluded a national study should and could be carried out. The following are the papers presented by consumers and academics on the cost-effectiveness of deinstitutionalization.

The case for cost-effectiveness -- the highest quality of support services for the least cost -- is most difficult to consider when community living is promoted as the only alternative. Objective research is suspect, for any evaluation assumes there are bound to be both strengths and weaknesses in any living situation in the range from institution to totally independent living. Advocates of independent living conclude the options should be limited, and researchers feel forced to defend their examination of the total continuum of care.

The CCSD advocates the provision of more and better community services for disabled persons, while examining the cost-effectiveness of support services provided along the continuum of care. This symposium combines both perspectives.

There is one excellent cost-effectiveness study model. The Weisbrod study of the Mendota Mental Health Institute in the USA is a pre-test post-test control group design (4). It compares a traditional hospital-based approach to treating the mentally ill with a non-traditional community-based approach. Patients were randomly assigned to either the acute treatment ward or to the community treatment program in which they were helped to confront and cope with the real costs of their actions. The experimental program cost an additional $800 per patient in a year, but in return it resulted in productivity (measured by earnings) of at least $500 and showed some evidence of improving patients' planning and decision-making skills. These patients' symptoms of mental illness decreased and their statisfaction with life increased.

Replication of the Weisbrod (et al.) study in Canada is most desirable. But much can also be learned from the experience of consumers and from research on parts of the cost-and-effect equation. These papers explore the costs and effects affecting the lives of persons who are physically, mentally, or psychiatrically disabled.

The presentors were chosen for their expertise and for their wide representation, as was the audience of 50 participants from experienced and theoretical backgrounds for the two-day meeting in Toronto in April, 1984.

The presentations are offered here in the order in which they were given. So, we begin with the six presentations on the subject of deinstitutionalization in the opening session, with a consumer and an observer speaking about each of the three disabilities.

Deinstitutionalization

About the mentally disabled, Kent Silzer notes the decline over the past 30 years from some 4000 to 200 residents in a mental hospital in Saskatchewan. He challenges the professional caregivers to seek out persons with the greatest need for mental health services, rather than wait for patients to come to them. Pat Capponi points out the positive and negative aspects of boarding out in the Parkdale area of Toronto. The positive side is the presence of community occupational therapists who are helping to form residence committees, the work of the supportive housing coalition, and the likelihood of more paraprofessionals helping "hands-on" (with shopping, bathing) with former psychiatric inmates. The negative side is that there are no regulations preventing crowding, no screening of boarding house residents, untrained staff who are poorly paid, poor diet and lack of privacy. Pat asks that we better understand what it means to have been badly prepared to go out into the community, and then to be poorly served there.

About the developmentally disabled, Françoise Brisson decries the lack of freedom in institutions from his own experience, and applauds the pluses of community living, such as seeing his parents often, receiving help from "People First", and being able to do such normal things as look for a job.

Jo Dickey depicts the starting point for advocacy -- parents establishing basic shared beliefs and values, including a desire for support services reflecting the strengths and needs of the individual being served. As well, they believe such services should help the individual to make decisions, monitor the delivery of such services, and allow personal network members unimpeded access to the individual. Jo Dickey goes on to describe how money for support services can be attached to individuals, and how brokers can help them walk their way through the service system. Five case examples are given of the cost-effectiveness of community living over institutional care. She concludes by challenging participants to examine how we can get quality of life for monies already being spent on community services for disabled persons.

About the physically disabled, Jacques Plamondon reports on the successful deinstitutionalization efforts of Centre François Charon. They can boast that 53 to 60 adults with limited mobility still live in apartments three years after deinstitutionalization, and four-fifths of them say they are "happier", "freer", "more responsible", and in a "better relationship with the community". The Centre estimates institutional costs to be about twice as much as apartment living, even for a severely disabled person. Jacques Plamondon closes by recommending that the providers of service be required to guarantee the number of service hours will continuously match the changing needs of consumers.

Tracy Carpenter believes the issue is not dollars, but what is going to give the best result for the money spent. Her personal and graphic experience is one of being over-serviced (institutionalized) and under-inspired (given low expectations and no training for independent living). She ends her presentation by asking that the focus of concern not be quality of life in institutions, but rather the development of community living situations for all disabled persons to learn to cope in real-life situations.

Costs

Laird Heal (University of Illinois) reports on the findings of a cost-comparison study of domiciliary costs in residential services provided by small and large facilities for developmentally disabled children and adults across the USA. Nearly three-fifths of the variation in costs is reported here as predictable from geopolitical, resident, facility, and staff characteristics. The authors conclude that normalization is economical.

Colleen Wieck (Minnesota) defends the need for cost-effectiveness studies, in that the direction and magnitude of deinstitutionalization may be determined by cost arguments. She continues by synthesizing the findings of three studies of variations in **per diem** costs (as affected by location, organizational structure, and resident characteristics). When day programming and support services are included, institutional and community care costs may be similar. But many alternative care models are both compatible with cost considerations and with political statements which promote normalization and least restrictive living environments, and we are urged to promote and create them.

Effects

Robert Flynn (Ottawa) defines the terms "deinstitutionalization", the WHO model of "impairment/disability/handicap", and the extent of disability in Canada. Through a review of the literature, he draws substantive and methodological conclusions as to how the planned cost-effectiveness study should address all three disabilities. "Program Analysis of Service Systems" (3rd edition) is suggested as a means of measuring service quality.

George Torrance (Ottawa) reports on a needs assessment study of the severely physically disabled in the region of Ottawa-Carleton. About seven per cent of the 232 study participants who were resident in institutions were found to be independent in all five basic self-care activities. The paper recommends that we identify the ideal number and distribution of beds and community services for a given population base for the three main disability groups.

A Synthesis

Judy Snow (Toronto) provides the wrap-up and the look ahead. She believes the first question we must answer is, "How can we support and create competent communities?" That is, communities which encourage **all** citizens to participate. The second question is "How much does it cost to create competence in the community?" That is, to learn from successful community programs already in place. Judy Snow concluded the two-day symposium with a challenge to "market the dream" of community living for all.

The Council is pleased that the invitational symposium brought together consumers, academics, and policy makers from across Canada to consider the costs and effects of deinstitutionalization. Some of the views may be new, certainly some of the research work is introduced here for the first time. Our apologies to the authors in the event editing changes altered their intent or misleads readers. If, after reading these papers, you believe a profile of disabled persons must be drawn, and a cost-effectiveness study like that by Weisbrod in the U.S.A. can and should be done here in Canada, please write a letter of support to the Canadian Council on Social Development.

Write: Harry MacKay, Ph.D.
Senior Research Advisor
Canadian Council on Social Development
55 Parkdale Avenue,
Ottawa, Ontario K1Y 4G1
Tel: (613) 728-1865

1. CCSD **"Deinstitutionalization: Costs and Effects"** -- A Literature Review, by Tom Jones, M.S.W. (52-item annotated, plus general biblio), March, 1984.
2. CCSD **"Deinstitutionalization: Costs and Effects"** -- Papers presented at an Invitational Symposium, April, 1984.
3. CCSD **"Deinstitutionalization: Costs and Effects"** -- Final Report by Harry MacKay, Ph.D. (as to the feasibility of a national study) April, 1985.
4. Weisbrod, B.A., Test, M.A., Stein, L.I. "Alternative to mental hospital treatment. II. Economic benefit-cost analysis." **Archives of General Psychiatry**, Vol. 37, No. 4, pp 400-405.

PART ONE

DEINSTITUTIONALIZATION

DEINSTITUTIONALIZATION OF PSYCHIATRICALLY DISABLED PERSONS

Kent Silzer, Ph.D.
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I will endeavour to describe the process I see occurring in mental health services, specifically in Saskatchewan, but more generally throughout Canada and North America.

In Saskatchewan, we have probably progressed further with the deinstitutionalization of the mentally ill than have other provinces, with the possible exception of Québec. In 1955, there were approximately 4,000 long stay patients in two grossly overcrowded mental hospitals in Saskatchewan. Now there are fewer than 200 persons who meet this definition in our one remaining mental hospital. To understand how this reduction in the number of patients was accomplished, we have to address two questions: where did the persons who were once patients go? and, where are the persons who might once have become patients going now?

Part of the answer to both questions almost certainly lies in improved methods of treatment. Some conditions, such as general paresis of the insane, have been eliminated by advances in physical medicine. Improvements in the general level of nutrition and hygiene have also served to reduce some other conditions. More importantly, the psychoactive medications have provided a means of relieving symptoms and have made it possible for many persons with mental disorders to function normally and to lead productive lives in semi-independent conditions. It seems appropriate to view many of the people who are capable of living semi-independently as handicapped persons rather than patients suffering from an active disease. Although improvements in treatment have allowed us to minimize these handicapping conditions in many situations, they have not enabled us to eliminate all handicapping conditions attributable to mental illness.

Although the utility of large mental hospitals was questionable long before the pharmacological revolution, its coming effectively redefined the problem. The challenge became one of developing more appropriate and more effective alternatives. By effective, I mean able to address the needs of the people the hospitals were originally created to serve, while being both practical and cost-effective.

What have we done and what happened to the persons who were once long stay patients in mental hospitals or who might have gone on to become long stay patients? I can posit the classical rule of thirds, although I have no evidence to suggest that those portions actually apply. Some of the people have almost certainly gone on to lead normal lives in totally independent living situations. There are reasonable numbers of such people. Some of these people, and I think it is important that we recognize this, have been and are being diverted into other institutions such as nursing homes and chronic care hospitals. They have been defined out of the mental health care universe and may or may not be better off because of it. It is interesting to note that the provinces with the lowest relative numbers of psychiatric beds are frequently the provinces with the greatest number of nursing homes and chronic care beds. The universe that we associate with mental health services has been contracting. Many of the people who once found themselves in mental hospitals were elderly and confused; such people are now usually cared for in a variety of other settings, most of which are not primarily identified with mental health. The mentally retarded had traditionally been grouped with the mentally ill, an association that was abandoned in most parts of Canada approximately 20 years ago (primarily for reasons of federal-provincial cost-sharing).

This brings us to a third group of people which is of primary concern to this group. I am talking about people who have significant psychiatric disabilities or who can be and are being maintained in community settings with varying degrees of success. It is this group of people which has recently received the most attention, although not necessarily the most assistance. I think we have all heard allegations about people being abandoned in the streets. Justifiable concern is being expressed about some of the residential settings in which these people are placed and about the quality of services that are (and too often are not) available to them in the community. On the other hand, we are still hearing concerns, often voiced by former patients, about some professionals who are still seeking to maintain control over all aspects of the lives of the psychiatrically disabled.

Mental hospitals, by virtue of their very nature, find it difficult to be anything other than total institutions. They tend to relieve their patients of responsibility for their own lives by determining needs and providing a package of services that a given individual may or may not require. They often encourage dependency relationships that are anti-therapeutic in the long-term and destroy prospects for rehabilitation. Many community settings, on the other hand, present the opposite extreme. They provide little assistance, or assistance in rather circumscribed areas, which fails to address the significant needs of many of these individuals.

Ideally, we will provide assistance and support to allow the individual to compensate for his or her disability. We seek to help them do those things they cannot be expected to do for themselves, while at the same time seeking to preserve the individual's ability to control and manage his or her own life to the greatest extent possible. Unfortunately, I think the typical experience shows that this is much more easily said than done.

The Saskatchewan Experience

The most active period of deinstitutionalization or, more properly, the decanting of the mental hospitals took place between 1955 and 1975 with the mid and late 1960's seeing the greatest reduction in patient numbers. There are fewer than 200 long stay patients currently resident in our one remaining mental hospital. Most of these people are elderly, and all but a few are likely to remain in institutional settings for the rest of their lives.

I think we had a couple of advantages. In a sense we began with virtually nothing, with the consequence that nothing had to be overturned before we embarked on new directions. The Province's human services were all but decimated by the Depression of the 1930's and did not develop during the Second World War. We ended up with very bad institutions that were grossly overcrowded and inadequately staffed, a common situation in Canada at the time.

After the war there was both a will and the means to take certain corrective measures. Plans were made throughout the 1950's and, in the late 1950's, Saskatchewan decided to adopt a modified form of a decentralized service delivery system that had been proposed by a working group of the American Psychiatric Association. Basically, the plan was to alleviate overcrowding in large mental hospitals by creating a number of smaller, nominal 300 bed mental hospitals, throughout the province. At the same time, and this had not been anticipated, effective psychopharmaceuticals were coming into widespread use.

The plan was implemented, or at least attempts were made to implement the plan, by developing a mental hospital, slightly smaller than the size recommended, in a small community called Yorkton. We were able to recruit adequate numbers of well qualified medical staff and social workers. Basically, we were attempting to maintain community ties with a view to being able to return, or least improve the prospects of returning, many of the individuals in the Yorkton centre to their home communities. Because of the introduction of effective psychopharmaceuticals and the availability of well qualified staff, this proved even more successful than anticipated. We found that we did not need a hospital as large as the one developed. Encouraged by this, our administrators were caught up in something of a developing zeitgeist that favoured not only decentralization but also the development of community services and support services.

We tried to decant our mental hospitals while at the same time severely restricting admission to psychiatric facilities other than acute care.

There was a period during the mid 1960's when we saw the type of development which I think is still commonplace in many parts of North America: large privately-operated quasi-institutional boarding homes threatened to become the institutional alternative. We had operators who managed specialized residential settings, some of whom dealt with rather large numbers of former patients, and some of whom provided accommodations in less than ideal settings. This course of development was thwarted by two unfortunate events that proved fortuitous in the long term.

Our mental hospitals were located in rural areas and were, in a sense, the mainstay of the communities in which they were located. Because of their economic importance, there was some organized opposition to the decanting process in the communities affected. Most of the arguments that were brought forward were based on the quality of care in the quasi-independent living situations in which patients were being placed. A ministerial commission was established to hear these complaints. While this issue was current, a former patient was involved in a spectacular mass murder in a rural community. This brought much more attention to the programs being offered.

Rather than thwart the developing community programs, and here I think much credit is due to the persons negotiating on behalf of our programs at that time, these events provided an incentive for improving them. Major improvements were made in two areas. We developed our "approved home program", which involved licencing community residential settings in which former patients and persons who might otherwise become patients were placed. A maximum limit of six individuals in any one home was established and strict physical standards were enforced. At the same time we developed a new breed of mental health worker, the community mental health nurse. The community nurse's primary function was, initially at least, providing follow-up services to persons who had been discharged, and to persons who might have become long stay patients, in a variety of community settings.

Because of the period during which these developments occurred, I think we successfully avoided some of the problems that have been experienced elsewhere. This is not to deny the existence of problems. We have experienced and continue to experience difficulties in bringing community and staff resources to bear on the problems of this group of patients who might otherwise be institutionalized. To some extent, we may then have regressed in this regard. Our staff, after a fashion, have become increasingly professional and have adopted both positive and negative attitudes associated with professionalism. They are too often willing to sit in their offices waiting for patients to come to them; they are quite willing to dispense advice, but not necessarily to go out and find those persons having the greatest need for mental health services. This is a problem we are attempting to address, with somewhat indifferent results.

Over the course of time we have adopted a number of other strategies, some of which are proving successful and some of which have yet to be evaluated. We have, for instance, provided additional support for self-help groups and have seen other self-help groups develop with no assistance. We have seen the development of new forms of sheltered employment, new recreational programs, life skills programs, training on-the-job programs, Fountain House-like members clubs, etc. Our staff has encouraged and supported most of these developments, although most are managed by non-governmental organizations.

I think it is obvious, on the basis of what I have said, that we do not have all of the answers. I certainly hope to learn something from this conference and to take new ideas back to my colleagues in Saskatchewan.

HOW PSYCHIATRIC PATIENTS VIEW DEINSTITUTIONALIZATION

Ms. Pat Capponi
Community Worker
Parkdale Activity and Recreation Centre
Toronto

I am going to speak from the perspective of the psychiatric patients. Most patients were, and still are, unaware of the benevolent basis upon which the deinstitutionalization movement was built. All that they know for sure is that someone or something had created radical change in their lives and their treatment. Now, somehow, being in hospital is supposed to be both good and bad for you.

I remember talking about deinstitutionalization to one earnest young hypochondriac who nodded and said, "You know I think I had that once." I did not know anything about it either until I experienced one of the many side effects of this policy. On or around 1978, I found myself unable to obtain decent housing here in Toronto. I was a patient on a psychiatric ward of a downtown hospital and, as such, I was turned away by a women's residence which was on a quota system for taking patients. Since I was unable to afford an apartment, the hospital finally referred me to a boarding home in Parkdale which is where my experiences began.

As some of you may be aware, the area of south Parkdale in Toronto has been inundated with psychiatric patients since the late '60s and the numbers have steadily increased, with estimates reaching as high as 3,000 individuals living in what amounts to a psychiatric ghetto. People have been sent into the community from Lakeshore Psychiatric, which is a provincial hospital now closed, Whitby and Queen Street Mental Health Centre. A large number have no previous address in Parkdale, or in Toronto for that matter, and certainly no friends or family in the area.

As near as I can understand, once the professionals had twigged to the fact that hospitalization creates its own problems and difficulties, the government and the doctors reacted as though bubonic plague had been discovered. Haste was deemed necessary to prevent further infection. It did not seem to matter that most of the people had long since experienced the worst the disease could do to them. Radical and instant surgery was performed in hospitals all over the country. With a bus ticket and the address of a boarding home, a hostel or the Sally Ann, thousands were supposedly saved from the dreaded onslaught of the institutional bug. The first truly criminal act performed by both the government and the professionals was that little or no attempt was made to prepare the patients for their departure, to get them used to the idea of living in the real world again. People who had been in hospital 10, 15 or 20 years were shown to the front door where a special kind of hell awaited them.

I have personally been hospitalized about seven times with the average admission being about five months long. Compared to the chronic psychiatric patients who were rushed to the streets, that is no time at all. My memory is still clear of how it felt around discharge time. The tremendous anxiety would steadily build; everything seemed to move so much faster outside and be so threatening. I remember, too, how aware the hospital staff, most of them on the psychiatric wards of general hospitals, were and how concerned about what kind of trauma could result from separation anxiety, they call it. Efforts were made to confront and deal with fears and get you back on your feet before you were discharged. I remember being unable to cook or shop or participate fully in life after discharge. There was a perceived need to carry around the walls of the institution because it was safer that way.

Multiply these feelings fifty times and you begin to understand just how debilitated and terrified a 10 or 20 year patient would feel when abruptly informed of his or her plastic cure and immediate release. With all this anxiety, it would be difficult enough to go out into a community in which supports were in place, and which was willing to accept you.

To step out into a vacuum is to step out into life. We must make an effort to understand the effects of hospitalization. Upon admission the patient is taught to mistrust himself and his feelings, to turn over complete responsibility for himself to others. He is browbeaten into accepting the authority of others over his bodily functions and every other matter that touches his existence. Cut off from the outside world and needing human contact, he is reduced to engaging in childlike phantoms and behaviour in order to gain a half hour from a therapist. He is taught that there is a pill for everything and that the most unforgivable crime or sin is refusing or pretending to swallow medications. Since he cannot do anything for himself, he eventually comes to expect and even demand that others do for him. The only skill he learns during the institutional incarceration is how to hook rugs, which will not do him much good in real life. He grows fat and lazy, his personality becomes unattractive, his conversation grows limited to a litany of complaints about the staff or other patients. The patient has been taught to be self-centered, dependent, over-medicated, understimulated and, most of all, placid. The first thing many patients did upon their release was to slice open a vein or jump out a window to win a ticket back to the only home they had known. Eventually, however, most had to face the fact that the door had slammed behind them.

Sensing a possible profit amid this misfortune, a number of speculators and operators opened boarding homes catering almost exclusively to the chronic ex-psychiatric patient. The houses they owned were in large old places, over-mortgaged and in varying states of disrepair. Into these homes and into the hands of less than scrupulous individuals came the ex-patient, clutching welfare cheques and drug cards and green garbage bags holding their possessions. No law or government agency watched out for them. No landlord and tenant act applied. No restraint was placed on numbers crammed into a room or the rent charged. Some houses cheerfully crammed five into a room and collected over $200 from each individual. People were charged for toilet paper. Every item, aside from the bed and three meals, were deemed extras.

Boarding homes hold from 30 to 70 people per house. There is no real screening procedure, so individuals who enjoy playing with matches, or violent individuals, alcoholics, everyone would be thrown together and left, often with no supervision or support through most of the daylight and evening hours. There is no such thing as trained staff; most houses hire cleaning people, one per house, and have them cook and distribute medication as part of their duties. Often the pay is far below minimum wage. Meals are the main social event of the day, with 30 or more individuals lined up for their quota of starch. Fruit and juice are rare occurrences. Medication, which tends to dramatically increase one's appetite, leave many hungry after meals and through the night. Aggression in the houses is met with aggression. Problems are handled with a baseball bat or other devices.

Often the client's only access to health care is through a dubious arrangement in which the landlord has contracted with a physician to be a house doctor. This can be a very lucrative arrangement for the house doctor who will spend two minutes per client performing no real examination or service and billing OHIP liberally. In some houses recreation is available in the form of a television set; in others, people just play cards or watch the ceiling. Many of the women in the homes are reluctant to bathe because bathrooms rarely have functioning locks. Showers are discouraged. Also, with 10 to 20 people using the same facility, it is rare to have an uninterrupted minute. Because of this and the shortage of money to pay extortion rates at laundromats, or even to buy detergent, lice are a common occurence.

For years this housing service was so cost-effective, charging only $7 a day compared to hospital rates of over $100 a day, that little was done to improve the quality of life for the people in these buildings. Various service agencies would sporadically intervene, but with no coordination they were rarely helpful.

Although we didn't have a mass murder, we did have a number of people going into the homes. Over four years of playing up the conditions has resulted in some attempt to clean up the situation. Agencies, such as the Community Occupational Therapist Association in Toronto, have gone into some of the homes to work with the tenants to form residence committees. Supportive Housing Coalition has recognized the need for different levels of housing and has established over 100 beds in the community, although none yet in Parkdale. One drop-in centre, where I work, was established in Parkdale and now serves over 90 people a day. But that still amounts to less than 15 per cent of the estimated ex-psychiatric population in the area.

Dr. Eva Gerstein, who was appointed to the mayor's action task force on discharged psychiatric patients, has called for a study into the effectiveness and purpose of over-medication of ex-psychiatric patients, and for a government-sponsored effort to upgrade and clean the boarding homes. She also recommended the establishment of a crisis house as an alternative to hospitalization.

Vocational and educational programs are now seen as necessary. We may have gone beyond the workshop mentality. The Archway Clinic, loosely connected to the Queen Street Mental Health Centre, has had its staff expanded by 10 case managers because I think it was recognized that professionals don't usually like to work "hands-on". Going with people and helping them bathe or shop is a very different situation from being in a uniform or sitting behind a desk. These were para-professionals that were hired at Archway. Program placement service, a loose attempt at coordination, and approved discharge planning will also soon be underway at Parkdale.

All these needs were created by the lack of supports for the 3,000 ex-patients in Parkdale. Yet no effort has made a substantial dent in the problems that we are encountering there. To make deinstitutionalization work the way it was meant to, all these supports and more are needed in the community. Otherwise, the ex-psychiatric patient population will not benefit at all, but continue to live in degradation, poverty and fear.

"I HAVE MORE FREEDOM NOW"

François Brisson
"People First"
Ottawa, Ontario

I have been in institutions for at least 24 years. When I was at Smiths Falls I was nine years old. The staff there did not treat me right, and I didn't have much freedom.

Then I went to Brockville. After Brockville, I went to Barrie. I had more freedom in Barrie, because I used to do more things. The shows were there and they were cheaper. We used to go see hockey games, and go out into the community and do things on our own. I liked Barrie more than the other institutions, because at the other places the staff didn't treat me right.

In Smiths Falls they would strike me and lock me in. You had to tell them where you were going. Barrie was not the same thing as Smiths Falls. Brockville was the same thing; you had to tell them where you were going.

My family appreciates that I am out in society, and I am improving a lot out in society. For eight years I have improved a lot, since I have been out. I get to see my parents more often. When I lived in Barrie, they used to come and see me once a month. My parents are pleased that I am out in society. I have no job yet, but I will when Leslie Laframboise of "People First" gets me one. He is supposed to get me on a farm in the summertime.

SOME NITTY GRITTY PROFILES

Jo Dickey
Executive Director
Community Living Society
Vancouver, British Columbia

We, in British Columbia, have gone through all the traumas of the last twenty-five years trying to get services for people who are labelled "mentally handicapped". About seven years ago, a group of parents felt that their sons and daughters were living in a very, very inadequate situation: the institution. They got together and decided that they wanted something better for their sons and daughters.

As I listened to Pat, I realized that there was an effect from the history of boarding home situations. The parents wanted something different for their sons and daughters. They realized that one of the major things missing was what they called a "fixed point of responsibility", or somebody who cared about their son and daughter as an individual.

During many deliberations throughout the months that followed, they developed a few basic beliefs and values. If I might share them with you, I think they will help you to understand where we are coming from. The parents believed that every person is a unique individual, having worth, no matter what the degree of handicap. They believed in a right to live a life of dignity, and they believed that every person must have his or her personal autonomy protected at all times. Every effort must be made to nurture development of self-determination for the individual. They believed that each person should have the opportunity to live as a full member of society in his or her own community.

Out of that spilled some basic principles. First, the focus of all supports must reflect the strengths and needs of the individual being served; second, a personal network must be in place to support the individual in making decisions and to monitor support services with, and on behalf of, the individual; and, third, access by the personal network to the individual served must be unimpeded and complete. Those of you who have anything to do with private enterprise will know that only a very exceptional person in private enterprise will allow access to the person in their particular premises at all times.

We went on to develop a brief for the government. At that time, we refused the government's offer to us, as parents, of millions of dollars to make a bigger and better institution. We said that we did not want this money from the Ministry of Human Resources of British Columbia, if it was not going to be put into the development of community living supports. Out of that complaint grew the Community Living Society which was funded by the Ministry of Human Resources. We asked that the money be attached to each individual, so that funds would travel with the individual as he or she moved.

Now the concept is there, in its infancy in a sense, because every time we turn around, we run into the fact that the rest of the system is not set up the way our system is set up, to concentrate on the individual. We support people in this way with what we call "brokers". The brokers do nothing but concern themselves with the individual throughout the system. They help my son get the very best service from the community. We felt that by tying the dollars to the individual, having someone walk hand-in-hand with the individual through the system, and having the "personal network" of an individual recognized within the system, there was absolutely no doubt that we were putting safeguards where there had not been any before.

When I think of the task that has been set out for some of you in this room, I get somewhat concerned. For some of us, there is no question about the cost of services being the determining factor for people who have been labelled "mentally handicapped", such as my son. We are so convinced that the community and small homes, which are well monitored and seen as the individual's home, are the only answer. It is such a strong belief that we can't see any other alternative. We have come to that conclusion. I just wonder whether in Canada we have gone further than trying to prove that something costs more or less. This concern with money has little validity in our dreams of the future for our friends. That does not preclude the fact that we have to make sure that the alternative we offer is not "pie in the sky", nor is it going to "break the country". In other words, it has to be cost-efficient. It is how we spend the dollars that is important, and what safeguards we put in place so that those dollars protect the quality of life.

I would like to share some experiences with you. I do this with an apology to the people I speak of, because I am going to paint a picture of them three and four years ago, and the picture is not flattering or current. But I think it is necessary because these people have been perceived as having extremely heavy needs and minimal chance of success in the community. There are people right across the country, in fact throughout the continent, of whom it is said, "they will always need institutions".

Fred was admitted to the institution in 1958 and discharged in 1982. He has epilepsy and would induce seizures for attention. He had unco-operative behaviour, he was argumentative, he made inappropriate sexual advances. Today, Fred lives on Elwell Street in Vancouver with three other people in their own rented home. He is on Handicapped Persons Income Assistance ($584.00 per month). His residential costs per month are $990.00 per month. He receives one-to-one support for twenty hours per month, which costs $209.00 per month, bringing the total cost to $1,199.00 per month. Within our system, because our dollars are attached to the individual, the one-to-one hours are broken down into hours for social experiences, hours for recreation, hours for going to the doctor, etc.

Sam lives on Newmarket Street. He is 17 years old. He was admitted to the institution when he was six. He moves in a wheelchair, and cannot transfer himself. He has scoliosis and impaired movement of hands. He spent days rolling on the floor in the institution. He had no interest in people; because of spasticity of lower limbs he required complete care in all skills, including eating. Today, he lives with two other teenagers on Newmarket Street. I saw him yesterday morning, going off to an integrated high school. He looks you in the eye, smiles at you, and says "good morning", in his communicative way. His residential costs are $3,122.62 per month; he is legally a child, so we cannot get one-to-one dollars for him. Sam does go to the emergency ward. I think he has been there three times this year. I think that there are people in this room who have probably been to the Emergency Ward three times this year as well. It is not unusual.

Helene lives on Ulster Street. She was admitted to the institution in 1957 at the age of 14 years. She came to the community in September of 1980. In the institution she was perceived as having aggressive behaviour problems, seizures, a slight stroke, and speech impairment. Today, she lives independently, volunteers her time because she cannot, at this time, get employment. She lives in a suite and her cost to the government is $543.00 per month Handicapped Persons Income Assistance, plus medical expenses which are covered by Assistance.

Lana is 55 years old. She was born in the institution. She has never been in a home in her life. She came out three months ago. She has never attended school. She had self-induced injuries; used simple phrases only; threatens others with physical harm; steals from peers. Three months later, after going into the community, she has a job in a plant shop that has been established by the Community Living Society. I am not pretending that she doesn't need support in the community, but she is doing jobs in that plant shop. She is starting to get into recreation. Lana lives with two other ladies in North Vancouver in a home that has been bought for them on Norwood Avenue. Her residential cost is $2,495.00 per month. Her one-to-one hours at this time are 75 hours per month, which is $787.00 per month. She gets GAIN, which is $584.00 per month. The total is $3,830.00 per month.

Arthur was admitted to the institution when he was seven years old, in 1965, with a hearing impairment. I do apologize to Arthur for relating his story. It sounds so negative. He had problems with his bathroom habits; he would eat fecal matter. He was addicted to nicotine. He ate cigarette butts, and had tantrums. When Arthur first came out he used to walk down the street and take lit cigarette butts out of peoples' mouths and eat them. Today, he goes down the street to MacDonald's by himself, buys coffee, pays for it and walks home with no incident. He goes to work every day, and the tantrums are very rare now. He lives on Springer Street with two other young people. He is learning to sign, and we have now brought him to the point that we have transferred his addiction to another method of dealing with it. We hope that some of the people in the medical profession can help us to help Arthur deal with his addiction in the future. But, for now, we have brought him to find a much more social way of dealing with that addiction. I am not proud of that, yet now he does not go down the street and rob cigarettes; he walks into a party where there are cigarettes all over the place and he does not touch any. His GAIN is $543.00 per month; his residential cost is $1,797.00; his one-to-one hours, 110 hours per month, is shared with other people. I have to put in the maximum there of $1,149.50 a month, which comes to a total of $3,489.50 per month.

All this is to say that we do have some costs of people returning to the community. The Community Living Society is not the only place where costs can be assessed. When we first asked that we be given an opportunity to get our sons and daughters out of the institution, we knew that we wanted to take people that others would write off. We did not want the "cream". We have taken people like Arthur. They told us that he was one of the most difficult people within the institution to support, and so we have purposely taken such people. We knew we had to acquire the skills to respond to their needs. We are not doing a tremendous job. We have so much to learn, but we are willing and we feel that we know what can be done. We feel that it is the commitment that is so necessary.

In terms of the dollars, there is not one of these people that is costing more to the community than he or she would cost in the institution. Now, to be fair, we have not talked about the medical care, we have not talked about schooling, we have not talked about the community recreation resources. It is very hard to assess how much it costs for you and me to go down to the community recreation centre, or to educate my other son; to make all those trips to the doctor in a year. I am not sure how those costs can be established or, indeed, whether they should be.

Just as a matter of record, in British Columbia, they have declared that they are going to phase out one of the institutions, which has 340 people in it, within a year. People are very concerned about how that is going to be done. They are attaching dollars to the individual, although whether they will attach dollars purely to the individual we are not sure yet. But at least they have given a figure, and plans are being developed and costed out based on strengths and needs of the individual. They have put money up front for the transition.

Some of us have been advocating this approach across the country. It will never happen if we are just going to try to bleed off one dollar at a time from the institution. I have to commend government for that approach. As we said, these are new dollars, separate from the dollars already being spent in the institution. This is absolutely necessary. We do have costs established already. We have at least three provinces, to my knowledge, and I am sure there may be more, that have committed themselves to returning people to the community from institutions, regardless of the cost. The important thing, then, is how we get quality of life for the dollars that are already being spent.

DEINSTITUTIONALIZATION:
ITS IMPLICATIONS AND REQUIREMENTS

Jacques Plamondon
Director of Rehabilitation Programs
Centre François-Charon
Québec, Québec

Since the late 60s, Québec has been experiencing a major revolution in the deinstitutionalization of various groups on the fringes of society (orphans, the mentally retarded and psychiatric patients). In light of the secularization of social services and structural and legal reforms, it became increasingly urgent to do away with setting apart in institutions those considered different from the "average person".

With health and social services reform and many rehabilitation and community intervention professionals arriving, integration of these persons into community life became a prime concern. At first, this movement affected psychiatric practice. A curative as well as preventive role was imposed on primary services (short term care hospitals and local community service centres. For children in difficulty, a whole series of less professional housing, such as foster families and group homes, were set up to recreate the family atmosphere so necessary to proper emotional development. Academic structures were made more accessible and special classes were developed with assistance from professionals to help these children and their parents.

The impact of a similar movement for the physically disabled was felt during the mid-Seventies. Associations for the promotion of disabled persons' rights played a prominent part in gaining recognition of their rights and claiming their rightful place in society. This led to a wide range of Québec legislation, including Act 9, the **Office des Personnes handicappées**, the Act respecting the **Régie de l'Assurance-Automobile du Québec**, and the Act respecting the **Commission de Santé et Sécurité du Travail**. Recently, the International Year of Disabled Persons increased public awareness of the concerns of the disabled and the resources needed. Within this context, the social affairs network had to review its models of intervention and of service distribution, which did not give due consideration to the specific needs of the disabled and to their desire to be integrated into the communities.

I will begin by describing the experiences of the social affairs network in the Québec City area from 1977 to 1982, then bring out the implications and the demands this extensive normalization movement represents for the disabled, the professionals and the State.

Experiments in Social Integration in the Metropolitan Québec City Area

In the spring of 1977, the Department of Social Affairs agreed to finance research submitted by "Les Habitations Plus" for three years. The research was continued by the Centre François-Charon following the amalgamation of these two agencies in 1979. The philosophy of the research was drawn from normalization and its implications and rested on the following three assumptions:

- There is clientele of adults with limited mobility living with their parents or in institutions who can live independently in an apartment, provided they are given physically and financially suitable accommodation and are provided with the support services their condition requires.
- Living in an apartment is likely to improve the quality of life for these persons and increase "normal" activities such as working and studying.
- Distribution of services to the disabled living independently is cheaper for the state than keeping these persons in an institution.

As first agreed, the Centre François-Charon undertook the evaluation part of the research program after three years of the experimental project, with the collaboration of experts from Laval University. The main purpose of the research was to determine the extent to which the project had met its objectives, the human and financial implications and the possibility of extending such services.

These were the results: the close contact with the Société d'Habitation du Québec resulted in the introduction of a series of physical and financial accessibility measures for the entire province. The Société:

- modified the selection criteria for subsidized housing to include adults with limited mobility;
- financed the cost of physical alterations to make existing subsidized housing accessible to the disabled;
- adjusted the functional and technical standards so that all subsidized housing under construction meets minimum requirements for accessibility; and
- introduced financial assistance for accommodation based on a formula of cost-sharing between the tenant and the Société d'Habitation du Québec.

Two hundred and fifty rent supplement applications were approved by November 1, 1980, throughout Québec.

During the project, 60 adults with limited mobility were moved into apartments, of which 53 were still living there in December, 1980. These people were young, single, had little education, were living on Social Aid and had moved out of families or institutions. Three types of assistance were necessary to make these moves possible:

- Home assistance, consisting mainly of physical assistance for bathing, getting up, going to bed, preparing meals and housework. This assistance was available seven days a week around the clock. A team of physical attendants made the rounds on a schedule that suited these people's work, school or recreation.
- Social and escort services, offered for four to six months, to prepare the disabled for apartment life and to ease adaptation to this new lifestyle.
- Financial assistance with accommodation, through the rent supplement formula.

To gauge the effects of these moves to apartments, we can state that the number of people who work or attend school has more than doubled since integration. More than 80 per cent of them say they feel happier, freer, more responsible and have a better relationship with their community.

Finally, the research made a fairly extensive comparison of the cost of integration, including that borne by the State (services, social assistance, transportation, etc.) and the cost of institutionalization. Results show that it costs about twice as much to keep a person in an institution as in an apartment, even a severely handicapped person (see appendix for table).

Bolstered by the preliminary results, the Centre François-Charon went further with its experiment and introduced a home-based support program in the summer of 1979. Since the Centre was aware of the great diversity in needs and social autonomy of the disabled, it set up a whole series of less intensive "normalized" housing facilities between 1980 and 1982.

The Chanoine Morel home, which was a halfway group home in 1977, has now been converted into a permanent group home within a residential district. The home accepts cerebral palsy patients who, because of their weight and some communications problems, need an attendant constantly. However, the youth of these patients and their desire to live as "normal" people make keeping them in institutions or totally dependent on elderly parents unjustifiable.

La Seigneurie residence, located in an apartment complex, provides accommodation for six persons, mostly hemiplegics, whose average age is around 50. They require physical assistance on a part-time basis. When this residence was opened, an educator introduced a program on everyday domestic activities.

"L'ilot de Pointe Ste-Foy" has 12 severely handicapped persons living on their own in a residential complex with many blocks of apartments. These persons have access day and night to physical assistance through a remote signaling system. Several of them study or take part in recreational activities in Ste-Foy.

"Foyer 204" is a group residence in the working class district of Limoilou; it houses five persons. Disabled people wishing to try out independent life in the community after a long period of institutional care or over-protection by their family can be admitted to this home for a period ranging from two to six months.

Lastly, in collaboration with the Centre des Services Sociaux for the Québec City area, we established three foster homes for persons who are more or less socially autonomous.

Severely handicapped persons who live alone or with their families within the Metropolitan Québec City area and who require continuous services can have access to physical assistance services 24 hours a day seven days a week through home care services. At present, 25 persons with limited mobility benefit from these services.

Because of the constraints of geography, work schedules and professional limitations, these services are not currently available through the Local Community Health Centres and the Community Health Departments in Québec City.

Deinstitutionalization: Its Implications and Requirements for Professionals and the Disabled

Since 1979-80, the Centre François-Charon has aided in the integration of about 350 persons with limited mobility under its program of support within the community setting. These persons were aged between 18 and 55 and their disabilities covered a wide spectrum: muscular dystrophy, cerebral paralysis, quadraplegia, hemliplegia and multiple sclerosis. Most of the clientele had long histories of institutionalization; they had little education and lived on welfare payments. Some were aphasic and communicated by using Blissymbolics or other devices.

Integration of this group would have been very difficult without the support of the rent supplement program or the existence of a "bank of homes" whose design makes them accessible to disabled persons. The support of a multi-disciplinary team was, in many cases, essential to the success of integration. The team comprised a social community worker, a community health nurse, a psychologist and an occupational therapist. This staff was also responsible for running the in-patient services of the Centre François-Charon, a factor facilitating integration into the community.

Occupational therapists play an extremely important role in assessing the physical abilities required in an non-institutional community. They also design the physical modifications to accommodation necessary for maximum autonomy of their clients.

However, after five years we have found that the extent of disability has less effect on the success of integration than the social autonomy of the person. The majority of failures we have experienced so far were much more closely related to psychological problems than to a lack of functional autonomy.

In this respect, it is essential that those who have spent a long time in institutions or have been over-protected by their family be psychologically prepared well before moving to an apartment. A person who has lived in an institution for any length of time becomes accustomed to behaviour conditioned by dependence on the nursing staff. His meals, dressing, basic needs and other activities are totally governed by the rigid routine and timetables of the staff around him. He now must learn to control his own time-table so as to meet his basic needs, plan a budget, sign a lease, deal with the grocer, the bank, his landlord and his neighbours. All this constitutes learning to socialize, something the person would not have previously done if he was handicapped from birth and placed in an institution at a very early age. Through a series of learning situations, he has to learn to identify his potentials and limitations and stop thinking of himself as totally dependent on the environment.

In many instances, especially for those born with the disability, this involves a long process of taking over responsibility for themselves. The process starts in the institution and continues with the support from community workers, once in the community.

This pattern of life demands courage and the ability to take risk, particularly for those with quadriplegia or cerebral palsy living alone in an apartment. They no longer have a bell within reach or a relative to attend to their needs at any time. They must gain acceptance by their neighbours, who are often not used to seeing a person in an electric wheelchair shopping or using other community services.

They need a lot of patience to explain to others the ways in which they are different and yet the same as any other citizen, with the same needs.

Mutual understanding between disabled and non-disabled persons must also be reached in community infrastructures. Our professionals have spent countless hours with the disabled, making municipal housing and recreation services, educational organizations and health centres more aware of the needs of the disabled. In some cases it is a matter of putting pressure on the authorities to make a particular public building accessible, in others of getting public swimming pools adapted to the needs of the disabled. These steps toward community integration were taken with the assistance of a dozen or so associations for disabled persons operating in the Québec City area. The local communities became more open to people who are different from others in some ways, but whose basic needs are no different.

Merely being able to live in a home that is physically and financially accessible is not, however, an end in itself. The disabled person, like any other citizen, needs to be a consumer, study and take advantage of the activities available in the community for his self-actualization.

Deinstitutionalization: Its Administrative Implications and Requirements

After five years' experience with normalization, we can now identify a number of requirements for the administration of services aiding integration into the community.

First of all, it is out of the question to organize such services along the lines of traditional service distribution like the social services centres (Centre de Services Sociaux) and the Community Health Departments, where professionals attend to a number of persons from 9 am to 5 pm, Monday through Friday. Disabled persons need assistance 7 days a week, often in the evenings and early in the morning. The staff for these services must therefore come from a central "hour bank" which guarantees a number of service hours to the disabled persons according to their changing needs, especially for persons suffering from a progressive illness such as multiple sclerosis or ataxia. This also means that the nursing and physical assistance staff have to carry out a wide range of activities, often in violation of the laws regulating professional practice.

A formula applied to persons disabled in traffic or industrial accidents sets aside a special budget which the disabled person administers himself to pay for assistance from his neighbourhood or the private sector. Even if this formula is not applicable to the entire disabled population, it has the advantage of getting around the administrative problems involving the particular "preserves" of the social affairs organizations as well as facilitating greater geographical mobility.

A formula like this one could be extended, in the form of a cash allowance enabling the person to buy the services needed to compensate for his or her limitations.

Any semi-public organization choosing these formulae finds itself caught between being an institution administering a number of beds for residential or extended care, or being bodies such as the LCSCs and the CHDs which provide out-patient services. Even though the first category tries to minimize costs and improve the quality of life for the disabled persons in the community, no encouragement to do so has come from the Department of Social Affairs, which instead prefers a system of beds and in-patient services. Furthermore, collective agreements are so rigid that any attempts at normalization are doomed to failure because of the legal and administrative battles they provoke.

As for the Local Community Health Centre and the Community Health Departments, they cannot stretch their meagre resources, presently devoted to temporary clients (the aged, single-parent families, etc.) at an average rate of 5 to 7 hours a week per client. Devoting about 15 hours a week to a disabled person, long-term, would, for all practical purposes, jeopardize the services already being offered to other short-term clientele.

In spite of the International Year of Disabled Persons in 1981, and the Socio-economic Conference in December, 1981, which involved many politicians, Québec is still awaiting a coherent and integrated policy on maintaining the disabled at home. This priority was brought out during these discussions, amid much publicity.

During the 1980-81 fiscal year, more than $800 million were spent in Québec on institutionalization, while during that same period the total expenditures on home-based services totalled $52 million. With the growing elderly population, whose physical deterioration caused by aging will increase the number of the disabled, it is unthinkable to continue to invest in an inflexible policy.

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APPENDIX

Comparison of Per-diem Costs According to Type of Accommodation and/or Groups as of October 1980

Accommodation and/or group considered	Per diem * (cost of services)	Global per diem **
The group of 49 persons in an accessible apartment within the experimental project (excluding those in "Foyer 204").	$11.18	$27.70
The group of 12 persons receiving services in their homes from Centre François-Charon	$37.18	$46.92
The group of 11 persons receiving services from Centre François-Charon via the "ilot de services" at service points.	$32.93	$49.53
The group of 298 persons living in the St-Augustin extended care hospital centre.	$71.56	$71.56
The group of 5 persons living at the permanent group home ("Le foyer 204").	$70.92	$86.26
The group of persons at the François-Charon Reception Centre ("J" Wing).		
Hypothesis 1	$137.19	$140.15
Hypothesis 2	$89.36	$92.32

* Per diem comprising only the physical assistance costs.

** Gross per diem comprising physical assistance costs plus social aid benefits, rent supplement where applicable, and transportation.

Source: Evaluative research on the experimental project "Logements accessibles et services de support". Clinical Activities Service, Centre François-Charon, January, 1981.

THE ISSUE ISN'T MONEY, IT IS QUALITY

Tracy Carpenter
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I have noticed from the speakers we have had so far this morning that there is really only a handful of people in this room who can speak on the issue of deinstitutionalization from the perspective of someone who has been through it. I have certainly been through it, and that is what I am most prepared to talk about today. Because there are few people speaking from that point of view, I recommend that what I have to say be given heavy emphasis, because you are going to be hearing several papers presented with dollars, figures, budgets, and so on. In my opinion, the issue is not dollars.

Let me explain with an example: If I was going to sell you a house, I might claim to have a house for you, a modest house, not too fancy. Now you could live in this house, but it is going to cost you $50 a day. You might think that sounds like a real bargain. You decide that you are going to live in this house. So in you go, and once you get there, you find out that the only catch is that the door is locked -- you can't get in; you can't get out. Whereas, on the outside, I might be able to find another house for you. Maybe it would cost $25 a day to live in that house. Maybe it would cost $125 a day to live in that house. The difference is, the door would not be locked. It might be in a better neighbourhood, it might be a better house, it might be more of what you want where you live.

I look at dollars and cents in the issue of deinstitutionalization the same way that I look at dollars and cents for anything else. First of all, I look at what I want, then I look at how much it is going to cost me. I have to decide which is the best bargain for my money. What is going to give me the most for my money?

To give you a little history, I was born in Ottawa, Ontario, so I have always lived in Canada. I left home when I was seven-and-half-years old and the reasons that I left home are, I think, very unjust. I would imagine that injustice is one of the reasons we are having this conference. I left home because I needed some services. First of all, I needed to be able to go to school, and the regular schools would not take me because I was physically handicapped. They felt that I did not qualify. The segregated schools would not take me, because I did not fit well enough into a therapeutic program. I was not going to get any better, so I would not look very good on their statistics. They could not make a nice little graph about me and show how much I was going to improve. So, I did not fit into a segregated system at that time either.

In addition, I needed a wheelchair. I had had to crawl around on the floor, or else my parents had to carry me in their arms, because we did not have money to purchase a wheelchair. So, because I needed some services, I had to leave my home in Ottawa, move to Toronto and come to live in a chronic care setting: Bloorview Children's Hospital in Toronto.

As you can see, what I needed were a few services. What I got was living in an institution for the next eleven-and-a-half years so that I could go to school, get a wheelchair and get a certain degree of services. In short, I got over over-served by the system. In order to get a certain amount of services that I did require I had to buy a whole set of goods, most of which I did not require. Many of the other young children who were living there at the time were in the very same boat.

Bloorview's age limit at that time was eighteen years. In 1976, I was old enough to leave. That was not very long ago -- eight years past. I was looking around for places where I could live after Bloorview. At eighteen years old, I had to leave. The age limit was up for me. I was very glad to leave, as you can imagine; but still, no services existed in the community, unless I was willing to consider other large nursing homes, senior citizens' homes and the like. I am sure many of the people here are quite familiar with the limited options for people with handicaps.

In addition to that, before I left Bloorview I was given many messages about what I could be, what would become of me, and where I should set my hopes. I was told not to get too encouraged about the fact that I was going to high school, because what was I going to do with an education anyway? I was given messages like, why should I try to be independent and do things for myself, because I was going to live in a nursing home, anyway? I was also told I would not need to learn to direct my own care. After all, why would I have to learn to do that, or learn about budgeting or paying bills, because, after all, I was going to live in a sheltered setting where that would all be done for me. So, obviously, if I had had a point of view of my own, I would just be putting a wrench in the whole institutional works.

This was said to me explicitly. This was not a hidden message, this was said to me time and time again by key personnel in the institution. So I did not receive any training. But I did get some messages indicating that the expectations for me were very low, and that all that was out there for me was a nursing home.

Needless to say, I did not leave my fate in the hands of any of the personnel at Bloorview. I started telephoning, writing letters and getting on any waiting list I could for places that offered independent apartment living with attendant care. Short of that, I was either going to live on the street, or find a friend to live with, or do anything but get into an institution. I had already had eleven and a half years of institutional experience. I certainly did not want to imagine the rest of my life doing that. I would rather have killed myself than go into another institution.

Finally, I found out that there was a place called Clarendon, in Toronto. It was the first apartment program for adults with physical handicaps. They had arranged for apartments which two or three individuals could share. Support services were available around-the-clock to provide whatever physical assistance you would require. You were on your own for everything else you would need. There was no counselling, no recreational services--all you had was the physical support services, which was great. Finally, I was getting exactly the kind of help that I had been needing all my life, and no more. I was not getting over-served.

Of course, there were problems when I left Bloorview, although in my view, they were really good problems. At least they were problems that were brought out from trying to cope with living in the regular community, not problems of how to adapt myself and become passive enough to enjoy living in the institutional environment. I think if someone can adapt to the institution, then they really have problems.

I learned what I needed to know about living outside the institution from the one or two people with whom I shared an apartment. They were a big help to me. They had already been living on their own for a while. I remember when I got my first phone bill, I did not know what to make of it. I didn't know which part was the total, which part to send in, or what you did with the computer card. That was what would be called a "life skill" in the institution. The moment I was on my own and had a bill I had to pay, all I had to do was turn to someone there and say, "What do I do with this?" I did not need a social worker with a Ph.D. or Masters to help me figure out what to do with the phone bill. I did not need to be over-served.

Of course, one of the disadvantages for people who live in an institution is that they lack the opportunities to form genuine, natural relationships with people on the outside. They only get to make relationships with people who are paid to be there with them, or with people who share the same label, who are all dumped together in the same place. I know from experience you do not have other people you can ask within the institution. The scope of resources at your disposal to find out the information you may need to know is very narrow. Whereas, on the outside, you can start making better contacts. You can make friends, you can meet with all sorts of people who can be resources to you in many different ways.

I was very interested in what Jacques said just a moment ago, about the social problems that he noticed people encountered in the other settings, the community settings. What I have found (and I don't need a study to figure this one out) is that those problems you discovered have been created by being in the institution. It is a logical consequence: you are segregated, you are put apart. You are at a distance from the rest of society. Then you are in a peculiar little environment, so you learn peculiar little ways of coping. Naturally, you transfer this behaviour when you go to the outside. The better solution is not to be in an institution in the first place. I sincerely hope there will be no subjects for such a study within a few years. Clearly, when you are learning social skills, learning them in real life is more relevant and has a greater impact.

Because of the many hats I wear, professionals frequently ask me what a resource person should include in a life skills program within an institution. I say, **move the people out of the institution, find out what they need to learn and start from there.** We professionals are in a position where we allow ourselves to be tyrannized by the developmental mode. We set up numerous situations and a long, long check list. We claim that when an individual has met all the criteria on the check list, he is ready to move out of the institution. I strongly disagree with that. If I had to wait until I answered every little check mark on a list before I got out of the institution, I would be there yet. You learn these things when you get out.

In closing, again I say the issue is not money, it is quality. When I left Bloorview in 1976, the per diem rate for children aged from infancy to 18 years was $110 per day. Both my sister and I lived in Bloorview, so at that time there was at least $200 per day going towards keeping my sister and I in the institution. If our parents had had $200 per week, we could have lived at home.

Obviously, there will be some people for whom community living expenses are higher than institutional costs. I say, "So what." They would be getting better quality service. They are in the community. They are not being stigmatized. It gives us more credit, as a society, for how we elect to treat people who need our support. We must focus on the most normalized options and leave out options that degrade people and do more harm than good.

We have to have a vision for the future, we have to look at what the world will be like 5, 10 or 25 years down the road. When I was in Bloorview, thinking about leaving at 18 years of age, no one foresaw that within five years there would be apartment settings with round-the-clock attendant care. No one foresaw that option. So no one thought about preparing me for it. Let's not get stuck in 1984. Let's start planning for 1990 and the year 2000. Let's think about what kind of world we want to have at that time.

PART TWO

COSTS

PREDICTORS OF DOMICILIARY COSTS FOR PUBLIC AND COMMUNITY RESIDENTIAL FACILITIES IN THE UNITED STATES

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Abstract

This paper reports on the cost of residential services to a large (n = 2271) probability sample of the United States' residents of public (PRF) and community (CRF) residential facilities for developmentally disabled children and adults. Some 50 geopolitical, resident, staff, and facility variables accounted for approximately 60 per cent of the domiciliary cost. Government ownership is especially dominant accounting for over 35 per cent of the cost variance. Adaptive and maladaptive behavior had expected cost effects. The region of the country had surprisingly predictable effects; facilities were more expensive in the Northeast and less expensive in the Southeast and West. Facilities were more expensive in large cities and less expensive in rural areas. Normalized conditions, those enhancing the freedom and dignity of the resident, were less expensive than restrictive conditions. These findings suggest that developmentally disabled citizens and the taxpayer would benefit greatly from a review of the system for providing these domiciliary services.

Deinstitutionalization of mentally retarded individuals has become one of the major social movements of the past decade. The present paper is based on a national survey conducted by Robert H. Bruininks and his associates at the University of Minnesota in the winter of 1978 and 1979. While Colleen Wieck based her dissertation on the cost data from this survey, she avoided direct comparisons of various types of facilities and she used the facility instead of the resident as the unit of analysis. The present paper extends her work by presenting a number of regression analyses in which daily domiciliary cost per resident is predicted by some 50 geopolitical, resident, facility, and caretaker characteristics.

Method

An intensive national search and mail survey of public (PRF) and community (CRF) residential facilities for developmentally disabled children and adults in 1977, located 266 PRFs and 4427 CRFs. Following this search, a national probability sample of 2271 individuals was selected for an intensive survey in the winter of 1978 and 1979. A two-stage probability sampling design was developed in consultation with the Survey Research Center at the University of Michigan's Institute for Social Research. In the first stage, a sample of 78 public and 180 community facilities was randomly selected from those identified in the earlier mail review. The probability of selection was proportionate to the number of mentally retarded residents and the distribution of facilities in the ten census regions.

Once facilities had been selected, residents were randomly selected within facilities (Stage 2). Sampling ratios were:

1:58	for CRFs
1:136	for PRFs
1:38	for PRF new admissions (those whose date of admission came after July 1, 1977)
1:38	for PRF readmissions (those whose date of readmission came after July 1, 1977)

These last two ratios were doubled to 1:19 and 1:6 respectively after about half the data had been gathered in order to provide the targeted national quotas of cases in these categories.

Data Collection

Trained interviewers from the Survey Research Center at the University of Michigan conducted standardized, on-site interviews. The protocol specified that the interview about any resident be conducted with the person who had been the resident's major day-to-day caregiver for at least two months prior to the survey; but only 1202 of the 1461 interviewees (83 per cent) strictly met this standard. Each interview, which lasted about an hour, covered daily activities and program plans, family and social contacts, specialized services, characteristics of the resident environment, and the physical, health, and behavioral characteristics of each resident. An administrator of each facility also completed a questionnaire disclosing extensive information about the physical plant, resident characteristics, staff characteristics and turnover, programs, ideology and planning, and detailed costs.

Of 180 CRFs originally selected, 154 (86 per cent) agreed to participate. Seven others were replaced by subjectively equivalent facilities from the same size class and census region. Of the 78 PRFs selected, 72 (92 per cent) agreed to participate. Three of the refusals were replaced from the same size category and region. Within CRFs, 1024 residents were originally targeted, and 965 were sampled, for a 94 per cent response rate. Within PRFs, 1373 residents were targeted (including 40 who were to be doubly counted as current residents and new residents and 10 who were to be doubly counted as current residents and readmitted residents), and 1306 were sampled, for a 95 per cent response rate.

Estimate of Domiciliary Cost

The challenge of a study comparing the housing costs of various types of facilities is developing a universal way to measure cost. Two disparities are especially common. First, in their estimate of average daily costs, PRFs include costs of non-residential day services as well as residential services, whereas CRFs typically include only the latter. Second, PRFs ordinarily include only operating costs in their cost-of-service estimates, and exclude the pro-rata cost of their buildings; whereas CRFs nearly always report their rent as a major cost item. For this reason, the questionnaires were developed to provide the basis for adjusting the reported per diem costs so that they could reflect only domiciliary costs, and reflect capital as well as non-capital domiciliary costs. Thus, the cost estimates used in the analyses below included per diem cost estimates that were coarsely corrected to reflect only domiciliary cost.

Results

The findings of these analyses will be presented in two ways. First, the simple bivariate correlations of cost with some 50 predictors will be shown. Second, multiple correlations and their component part correlations will be featured. In each case, analyses will be shown for total subjects and for five specific subject types separately: CRFs with 15 fewer residents, CRFs with 16 or more residents, PRFs, new admissions and readmissions to CRFs, and new admissions and readmissions to PRFs. Readers should refer to the appropriate table.

Table 1.
Daily Domiciliary Cost for Five Classes of Resident.

a. PRFs cost more than CRFs.

b. Large CRFs cost more than small.

c. New admissions and readmissions do not differ appreciably from current admissions, but this result is tempered by the sampling constraint of the study, since facilities were selected before residents.

Table 2.
Simple bivariate correlations between cost and all predictors used in these analyses. Correlations greater than .2 are statistically significant.

a. Of the geopolitical predictors, only location in the Northeast was associated with higher costs.

b. Looking at personal variables, high costs were associated with low adaptive ability, aggression and self-abuse, and to some extent with secondary handicaps and length of stay in the respondent facility.

c. Ownership was highly correlated with cost: public ownership was expensive, family ownership or for-profit ownership was inexpensive.

d. Normalization was inexpensive. Several proxies of this construct apply: expensive facilities were less homelike, blended less with their neighborhoods, were more often isolated, were larger, and offered their residents less autonomy.

e. Staff were more satisfied in less expensive facilities. Caregivers expressed greater satisfaction and had less turnover in these facilities. However, less expensive facilities also had more missing data on these variables, which may imply that smaller facilities are less willing to report negative information than larger, more impersonal facilities.

Table 3.
Simple bivariate correlations for small community facilities.

a. Location was apparently very important in determining the cost of these facilities. They were more expensive in the Northeast and less expensive in the South. Furthermore, they were more expensive in the inner city and in areas of higher per capita income, and less expensive in rural areas.

b. Resident variables were not highly correlated with cost. It seems that resident characteristics would be most likely to reveal themselves in the small CRF analyses, since the two-tiered sampling strategy (facility first, then residents) was least constraining here.

c. Family operations were less expensive. This was explicit in the family ownership correlation, and implicit in the negative correlation between missing data for resident-to-staff ratio, job satisfaction, job turnover, and staff starting salary.

d. The staff of more expensive residents in small facilities had more years of formal education.

Table 4.
Simple bivariate correlations for large community facilities.

a. Region of the country affected cost very little.

b. Large community facilities, like small ones, were more expensive in the inner city and less expensive in rural areas. Again, counties with higher per capita income had more expensive facilities.

c. It cost less to house more able residents, when ability is reflected in an adaptive behavior score, ambulatoriness, or number of secondary handicaps.

d. The less expensive facilities had more missing data, suggesting that they invest less in administrative overhead.

Table 5.
Simple bivariate correlations for public residential facilities.

a. The familiar cost pattern is accented: PRFs were more expensive in the Northeast, and less expensive in the South and West.

b. Paradoxically, a county's unemployment rate is **positively** correlated with cost. Apparently, deinstitutionalization-inspired job terminations in a PRF, often the major industry in a county, drive up the unemployment rate of the county at the same time as they drive up the average daily cost of institutional care.

c. Staff turnover was greater in less expensive facilities, possibly suggesting that deinstitutionalization is more prevalent in these facilities.

d. Starting salary was correlated with cost. What is surprising is that this correlation is so small and that it was not correlated with CRF domiciliary costs.

Table 6.
Simple bivariate correlations for new admissions and readmissions to community facilities.

a. Geopolitical variables were unimportant.

b. Older, heavier residents were less expensive.

c. Adaptive behavior and ambulatoriness reduced cost, but maladaptive behavior did not increase it.

d. An institutional image was associated with higher costs. Government ownership, size, and distance to the nearest shopping center were all associated with higher cost; family ownership, missing data, and high home-like ratings were all associated with lower cost.

Table 7.
Simple bivariate correlations for new admissions and readmissions to PRFs. These correlations are trivial, since the same facilities were involved as for slide 5.

Table 8.
Overall regression analysis. This analysis included all 2271 residents. Classes of resident were included in the analysis in the form of orthogonal contrast variables. Seven blocks of variables were entered in a pre-specified order:

a. Geopolitical variables
b. Resident characteristics
c. Resident/staff ratio
d. Facility orthogonal contrasts
e. Staff characteristics
f. Facility characteristics
g. Staff starting salary

This particular order was selected for the following reasons:

a. We felt that regional economic differences should be controlled statistically before any substantive predictors were investigated.

b. We felt that facilities often attribute their high cost to the type of resident they serve, and to judge facilities, that variance attributed to resident characteristics should be partialed out first.

c. We entered resident-per-staff ratio next because we regarded it as a proxy for those resident characteristics that we were unable to measure directly.

d. Facility contrasts were entered next because we were most interested in the simple question: Which class of resident costs more? We entered five contrasts. Two of these compared new and readmitted residents with longstanding residents, on the grounds that new and readmitted residents are presumably more difficult, crisis cases, and therefore more costly. A third compared small and large community facilities. A fourth compared CRFs and PRFs.

e. Staff characteristics were entered next to determine if they could account for any variance beyond that already accounted for.

f. Facility characteristics were entered next to determine if they could account for any variance beyond that already accounted for.

g. Starting salary was entered primarily as a check on the quality of the variable selection in the prior blocks of predictors. The rationale, which was undermined by the low correlation of cost with starting salary (Table 2), was that if the prior predictors were well chosen, there should be no variance added by starting salary; but if prior predictors were poorly chosen, there should be considerable variance added by this last block.

Table 8 shows that cumulative squared multiple correlation as each of these blocks of predictor variables is added to the prediction of costs. This squared correlation is, of course, the proportion of variance in cost that is accounted for (removed from unknown or "error" variance) when predictor information becomes known.

a. Costs are highly predictable. The final squared multiple correlation of .58 indicates that nearly three-fifths of the variance in daily domiciliary resident cost is predictable from geopolitical, resident, facility, and staff characteristics.

b. The region accounted for about 8 per cent of the total variance.

c. Resident characteristics added about 12 per cent to the prediction of cost.

d. Resident-per-staff ratio added another 8 per cent.

e. Facility contrasts added a great deal, roughly 24 per cent of the total variance.

f. Beyond knowing the facility type, knowing staff characteristics, facility characteristics, and staff starting salary, each contribute about 2 per cent to the total cost variance.

Table 9.
Part correlations for individual predictors from the overall regression analysis.

a. The overwhelming feature of this figure is the huge (24 per cent) squared part correlation for the CRF versus PRF contrast variable. The large correlation (.62) between government ownership and domiciliary cost seen in Table 2 has survived the assault of regional and personal attributions, and public ownership looms as the vastly dominant determinant of the domiciliary service for these residents.

b. Regional differences are, as noted above, large and statistically significant.

c. Personal characteristics are important. Adaptive behavior, aggression, self-abuse, secondary handicaps, and length of stay all contributed predictably to housing costs. Furthermore, resident-to-staff ratio and the absence of data on this measure had predictable effects on cost.

Table 10.
Separate global regression analyses for each class of resident. These analyses parallel that of the last table, except contrasts among resident classes (facility contrasts) are preempted. When classes of residents are viewed separately, the multiple correlations are nearly as large as when they are viewed in concert, despite the fact that the class of resident was the dominant variable in that analysis. Tables 11 through 15 show the cost variance added by individual predictor variables.

a. The PRF profile differs noticeably from the two CRF profiles, which do not differ from each other. In all cases there are regular increments in the squared multiple correlation (cost variance accounted for) as blocks of predictor variables are added to the regression equation, except that staff starting salary (the last block) adds little.

b. The cumulative predicted variance for new admissions and readmissions differs strikingly from that of longstanding residents, especially for CRFs. The cost of new admissions and readmissions to CRFs is nearly independent of region, and greatly dependent upon resident and facility characteristics. A similar but less striking divergence is apparent in the two PRF profiles.

Table 11.
Squared part correlations for small community facilities.

a. Region was a dominant predictor.

b. Missing staff ratio was the most dominant cost predictor, accounting for about 15 per cent of the cost variance. This variable presumably reflects the low cost of family operations, which did not complete the section of the questionnaire that contained this item.

Table 12.
Squared part correlations for large community facilities.

a. Reflecting the bivariate correlations, region of the country was not a potent predictor of cost, but location was. Large CRFs located in cities with low unemployment were more expensive than those located in rural areas with high unemployment.

b. The second major determinant cost in large CRFs was the ratio of residents to staff. This finding is surprising only in that it is so weak here and in other resident classes.

Table 13.
Squared part correlations for PRFs. The figure for the separate predictors is as uninteresting as the global summary shown in Table 10. The only interesting feature is the positive correlation of unemployment rate with housing cost, which was noted in Table 5. The correlation holds for all regions of the country.

Table 14.
Squared part correlations for new admissions and readmissions to CRFs.

a. Mysteriously, weight appears as the dominant resident characteristic correlated with cost. Slender new and readmissions cost more.

b. More reasonably, it was less expensive to enroll a new admission with higher adaptive skills.

c. Larger facilities were more expensive for this class of resident.

d. These residents cost more when they were admitted to facilities that lie a long distance from the nearest shopping center.

Table 15.
Squared part correlations for new admissions and readmissions to PRFs. This profile is similar to that for PRFs in general, a finding that presumably reflects the sampling design, more than the reality of the cost of serving this class of resident.

Conclusions

Several conclusions seem warranted on the basis of these results.

1. Public facilities are expensive facilities. While part of this expense can be attributed to the dominance of fixed costs in PRFs, which cause average costs to rise when residents are released, there has been ample time for these costs to dissipate. We must assume that the cost of service includes layers of administrative bureaucracy whose main function is to keep one another busy. Community facilities, even when they must respond to the paperwork of the bureaucrats, have much lower administrative overhead.

2. The common assertion that the PRF costs are driven up because the facilities serve the difficult behavior problems and serious medical cases is probably 55 per cent myth. These factors account for about 45 per cent of the predicted cost variance.

3. Normalization is economical. Whenever proxies of resident freedom and dignity found their way into a prediction equation, they were seen to reduce costs.

4. There is a serious anomaly in the cost of direct service to residents. Nominally, domiciliary service is a labor-intensive industry, whose primary cost should be that of labor. However, the low correlation between cost and either starting salary or resident-to-staff ratio suggest that a careful review of these services is long overdue. Where is the money going? Who is collecting money for services to developmentally disabled children and adults if the direct care staff are not?

5. There are huge regional differences in the cost of domiciliary service. Are these differences justified by service quality?

Table 1

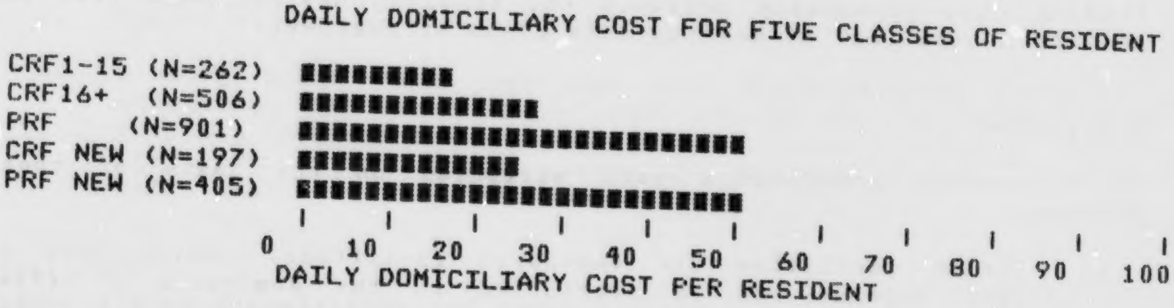


Table 2

ALL FACILITIES - 2271 CASES

```
                -1   -.8  -.6  -.4  -.2   0    .2   .4   .6   .8   1
                 |    |    |    |    |    |    |    |    |    |    |
SOUTHERN USA                            000
WESTERN USA                            0000
EASTERN USA                               00000000
INNER CITY                                00
SUBURBIA                                 00
RURAL                                    00
UNEMPLMT RATE                             000
PERCAP INCOME                             0
SEX                                       0
WEIGHT                                  000
NONAMBULATORY                             000
AGE                                     000
MONTHS IN FAC.                            00000
NO. 2NDRY HANDIC.                         00000
ADAPTIVE BEH                        0000000
AD BEH SCR MSG                            0
AGGRESSION                                00000
SELF-ABUSE                                000000
VISITS TO FAMILY                        000
VISITS BY FAMILY                          0
RES/DOMESTAFF                         00000
R/DS MSG                              00000
OWNED BY GOVT                             0000000000000000
OWNED BY FAMILY                    00000000
OWNED FOR PROFIT                     000000
UNHOMELIKE                                000000000000
UNHOMELIKE MSG                            00
BLEND WITH NEBRHD              000000000000
NO NEBORS                                 00000000
NEBRHD BLEND MSG                   00000000
LICENSED MR BEDS                          000000000000
DAY ACTVTY AWAY                         000
NO DAY ACTVTY                             00
DISTANCE TO SHOP                          000
NOM ADMIN PBS                             00
RES AUTONOMY                        0000000
AUT SCORE MSG                             00
STAFF EDUCATION                           0
STAFF TENURE                              000
STAFF JOB SAT                        000000
STF JOBSAT MSG                     00000000
STAFF TRNOVR                        0000000
STF TRNOVR MSG                        00000
MR SVC AT FOLWUP                          00
STAFF START SAL                           00000
STF STARTSAL MSG                   00000000
                 |    |    |    |    |    |    |    |    |    |    |
                -1   -.8  -.6  -.4  -.2   0    .2   .4   .6   .8   1
                CORRELATION WITH DAILY COST PER RESIDENT
```

Table 3

COMMUNITY RESIDENTIAL FACILITIES WITH 15 OR FEWER RESIDENTS

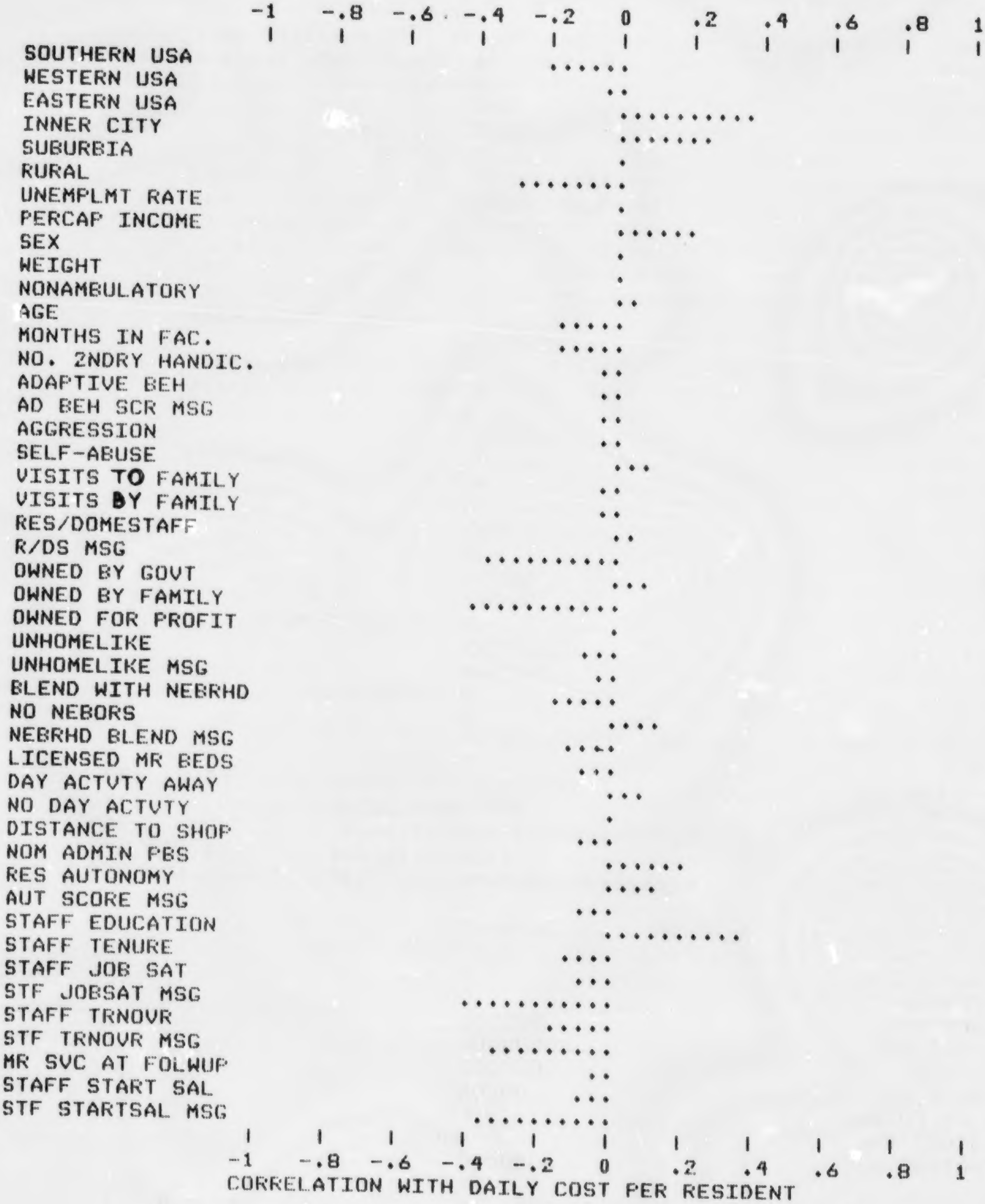


Table 4

COMMUNITY RESIDENTIAL FACILITIES WITH 16 OR MORE RESIDENTS

```
                   -1  -.8  -.6  -.4  -.2    0   .2   .4   .6   .8    1
                    |    |    |    |    |    |    |    |    |    |    |
SOUTHERN USA                               ooo
WESTERN USA                                  o
EASTERN USA                                  oo
INNER CITY                                   oooooooooo
SUBURBIA                                  oooo
RURAL                                   oooooo
UNEMPLMT RATE                           oooooo
PERCAP INCOME                                ooooooooo
SEX                                         oo
WEIGHT                                  oooooo
NONAMBULATORY                                ooooooooo
AGE                                     oooooo
MONTHS IN FAC.                               o
NO. 2NDRY HANDIC.                            ooooooo
ADAPTIVE BEH                           ooooooo
AD BEH SCR MSG                               o
AGGRESSION                                   oo
SELF-ABUSE                                   oooo
VISITS TO FAMILY                           ooo
VISITS BY FAMILY                             o
RES/DOMESTAFF                        ooooooooo
R/DS MSG                                oooooo
OWNED BY GOVT                                oooo
OWNED BY FAMILY                            ooo
OWNED FOR PROFIT                            oo
UNHOMELIKE                                   ooooo
UNHOMELIKE MSG                              oo
BLEND WITH NEBRHD                        ooooo
NO NEBORS                                    ooo
NEBRHD BLEND MSG                           ooo
LICENSED MR BEDS                             oo
DAY ACTVTY AWAY                            ooo
NO DAY ACTVTY                            ooooo
DISTANCE TO SHOP                             o
NOM ADMIN PBS                                oo
RES AUTONOMY                              oooo
AUT SCORE MSG                                ooooo
STAFF EDUCATION                              oooooo
STAFF TENURE                              oooo
STAFF JOB SAT                           oooooo
STF JOBSAT MSG                           ooooo
STAFF TRNOVR                               ooo
STF TRNOVR MSG                         ooooooo
MR SVC AT FOLWUP                           ooo
STAFF START SAL                           oooo
STF STARTSAL MSG                       ooooooo
                    |    |    |    |    |    |    |    |    |    |    |
                   -1  -.8  -.6  -.4  -.2    0   .2   .4   .6   .8    1
                   CORRELATION WITH DAILY COST PER RESIDENT
```

Table 5

PUBLIC RESIDENTIAL FACILITIES

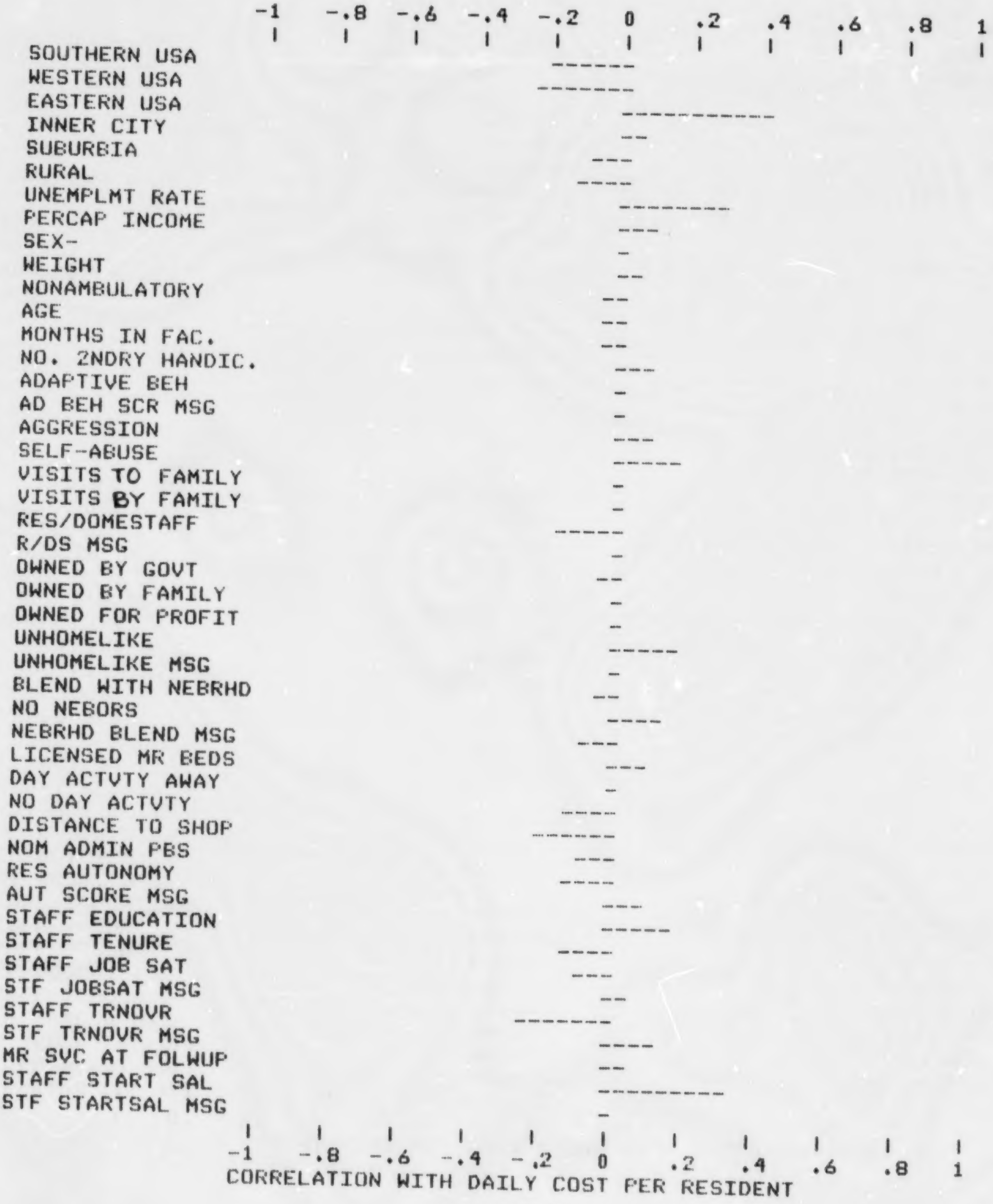


Table 6

NEW ADMISSIONS AND READMISSIONS TO COMMUNITY RESIDENTIAL FACILITIES

```
                    -1  -.8  -.6  -.4  -.2    0   .2   .4   .6   .8    1
                     |    |    |    |    |    |    |    |    |    |    |
SOUTHERN USA                                  ++
WESTERN USA                                 +++
EASTERN USA                                   ++++
INNER CITY                                    ++++
SUBURBIA                                     ++
RURAL                                      ++++
UNEMPLMT RATE                               +++
PERCAP INCOME                                 +++
SEX                                           +
WEIGHT                                  +++++++++++
NONAMBULATORY                                 +++++++++
AGE                                   +++++++++
MONTHS IN FAC.                                +++
NO. 2NDRY HANDIC.                             ++++++
ADAPTIVE BEH                          +++++++++++++
AD BEH SCR MSG                               ++
AGGRESSION                                    +++
SELF-ABUSE                                    +++
VISITS BY FAMILY                            +++
VISITS TO FAMILY                            +++
RES/DOMESTAFF                            ++++++
R/DS MSG                                  +++++
OWNED TO GOVT                                 +++++++++
OWNED BY FAMILY                          ++++++
OWNED FOR PROFIT                          +++++
UNHOMELIKE                                    +++++++
UNHOMELIKE MSG                                ++
BLEND WITH NEBRHD                             +
NO NEBORS                                     +++++
NEBRHD BLEND MSG                          +++++
LICENSED MR BEDS                              ++++++++
DAY ACTVTY AWAY                              ++
NO DAY ACTVTY                                 +++
DISTANCE TO SHOP                              ++++++++++
NOM ADMIN PBS                                 +
RES AUTONOMY                              +++++
AUT SCORE MSG                                 ++++++
STAFF EDUCATION                               +++
STAFF TENURE                                  ++++
STAFF JOB SAT                             +++++
STF JOBSAT MSG                            +++++
STAFF TRNOVR                              +++++
STF TRNOVR MSG                           ++++++
MR SVC AT FOLWUP                           ++++
STAFF START SAL                              ++
STF STARTSAL MSG                          +++++
                     |    |    |    |    |    |    |    |    |    |    |
                    -1  -.8  -.6  -.4  -.2    0   .2   .4   .6   .8    1
                    CORRELATION WITH DAILY COST PER RESIDENT
```

Table 7

NEW ADMISSIONS AND READMISSIONS TO PUBLIC RESIDENTIAL FACILITIES

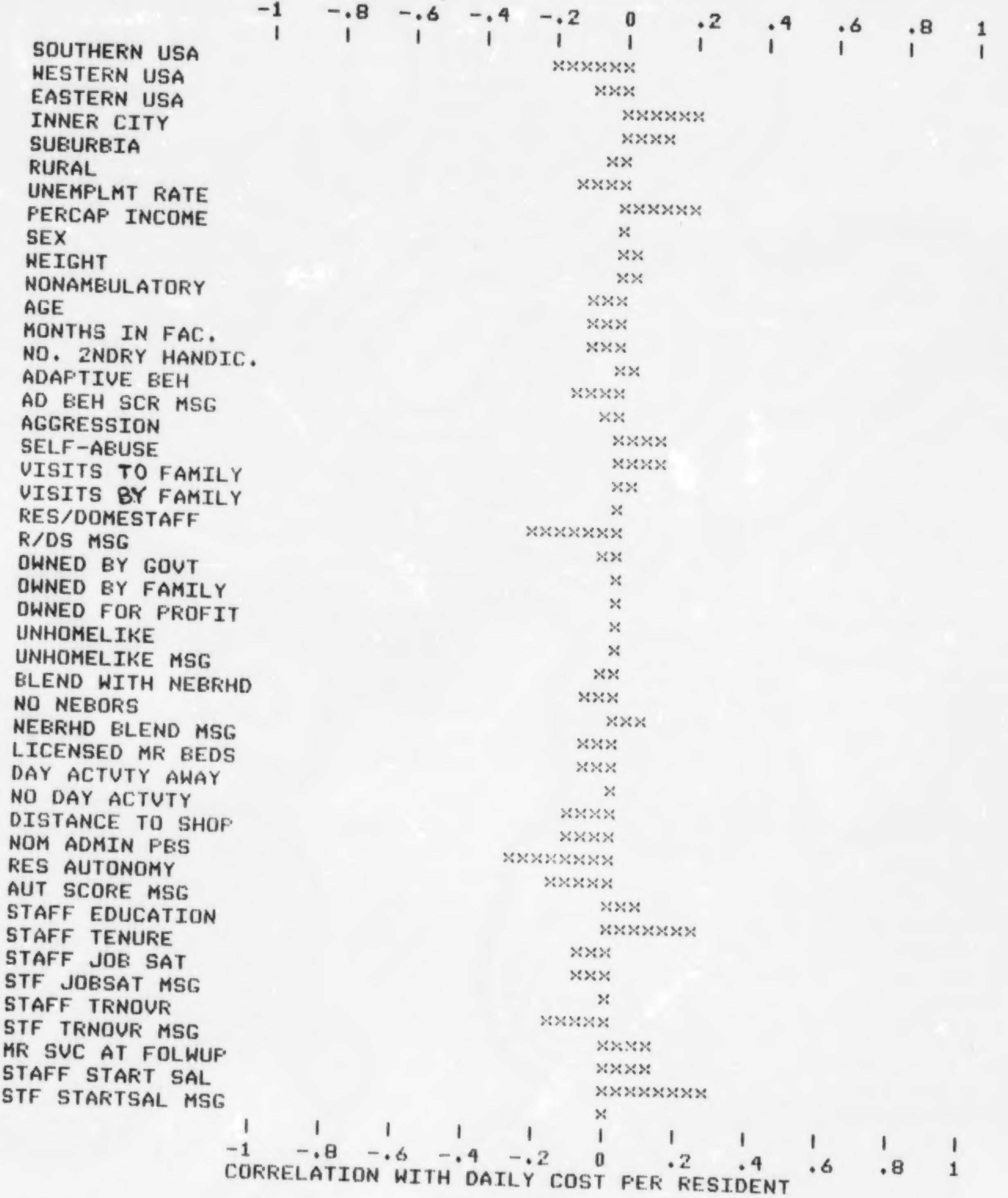


Table 8

DAILY DOMICILIARY COST OF EACH RESIDENT PREDICTED BY REGIONAL, INDIVIDUAL, FACILITY, AND STAFF CHARACTERISTICS

```
REGION           00000
RESIDENT CHARACT.00000000000
RES/STAFF RATIO  000000000000000
FACIL. CONTRASTS 000000000000000000000000000
STAFF CHARACT.   0000000000000000000000000000
FACILITY CHARACT.00000000000000000000000000000
STAFF STARTNG SAL000000000000000000000000000000
                 |    |    |    |    |    |    |    |    |    |    |
                 0   .1   .2   .3   .4   .5   .6   .7   .8   .9    1
               CUMULATIVE SQUARED MULTIPLE CORRELATION
```

Table 9

PART CORRELATIONS FOR THE TOTAL DATA SET (N=2271)

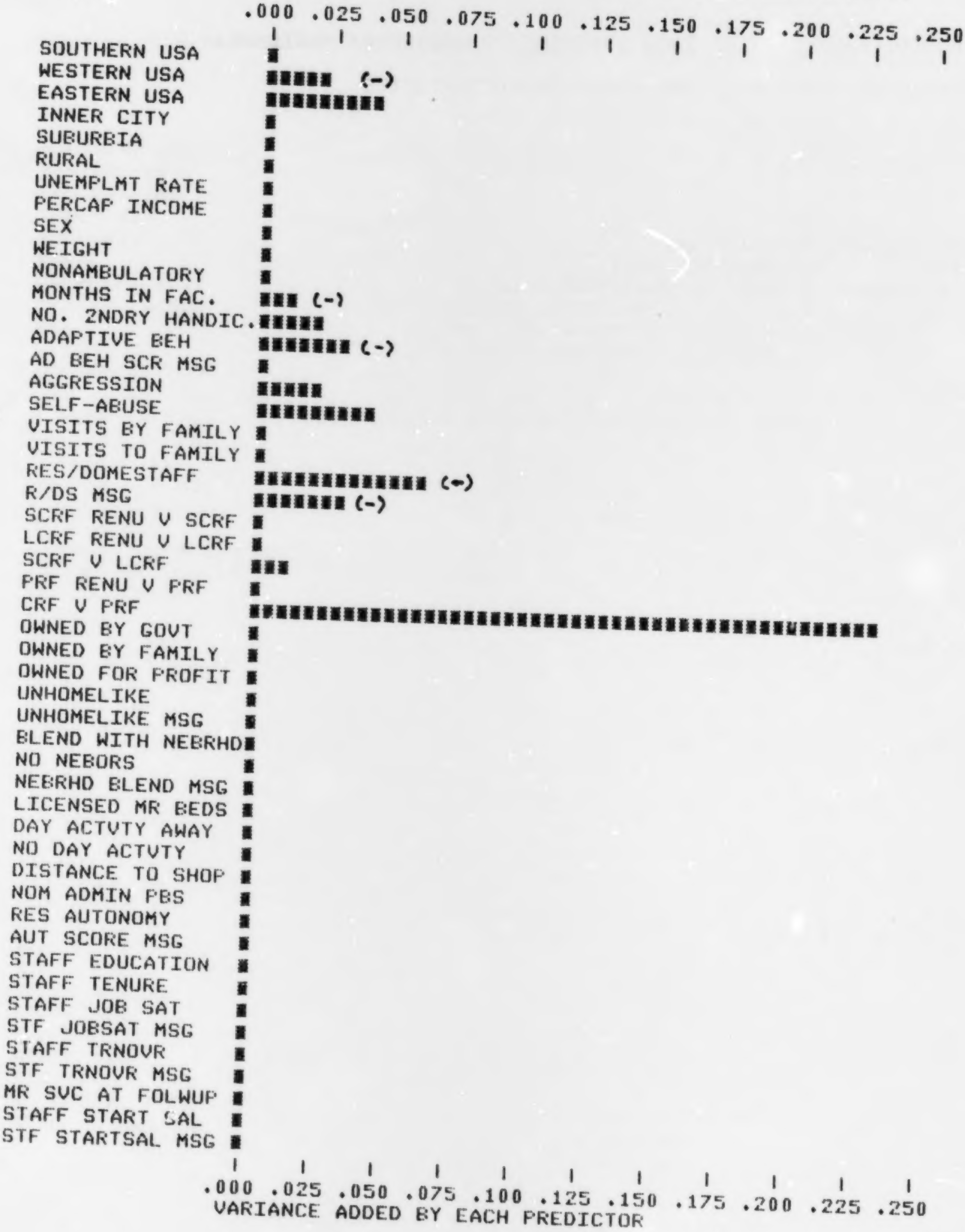
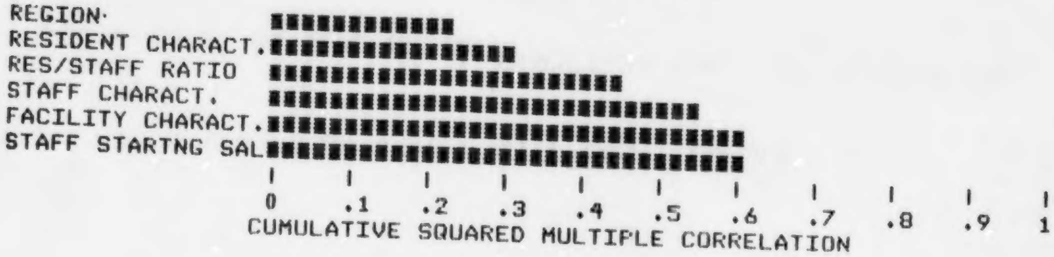
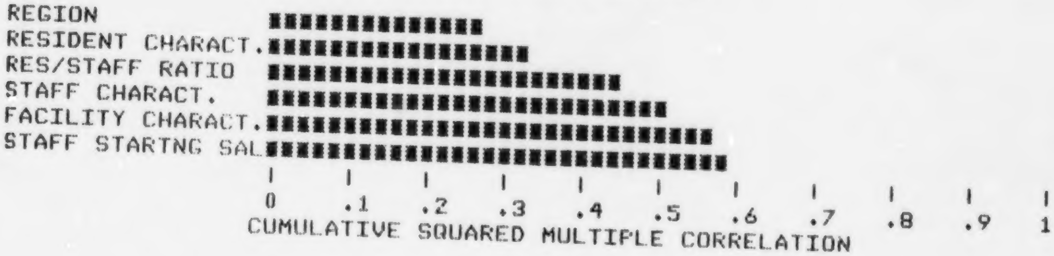


Table 10

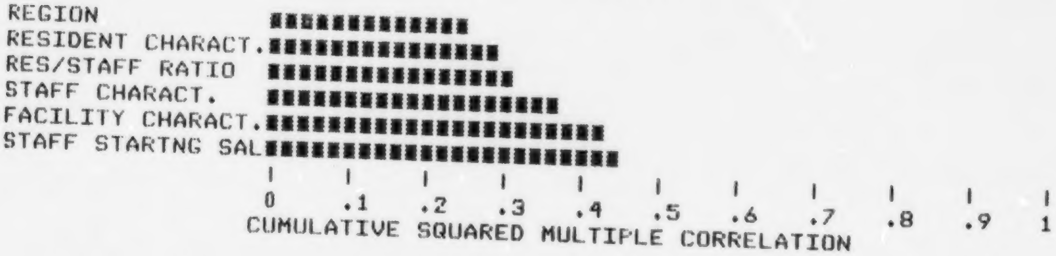
CRF WITH 15 OR FEWER RESIDENTS



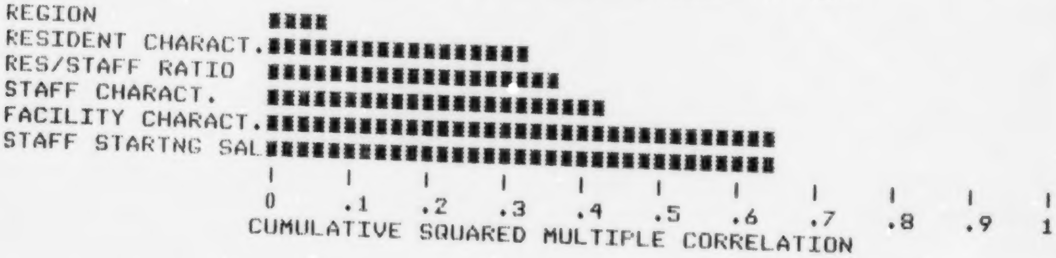
CRF WITH 16 OR MORE RESIDENTS



PUBLIC RESIDENTIAL FACILITY



NEW ADMISSIONS AND READMISSIONS TO CRFS



NEW ADMISSIONS AND READMISSIONS TO PRFS

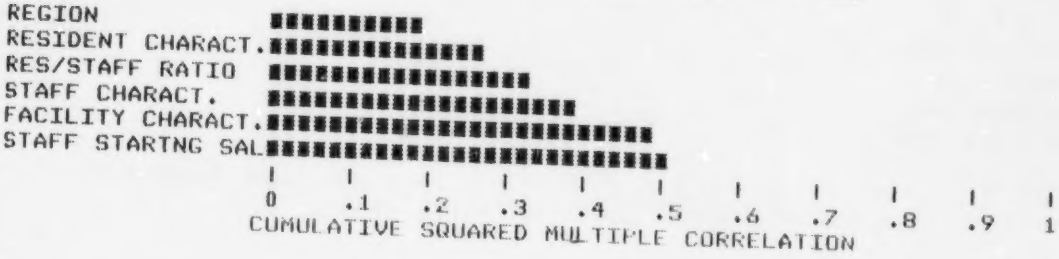


Table 11

CRF WITH 15 OR FEWER RESIDENTS

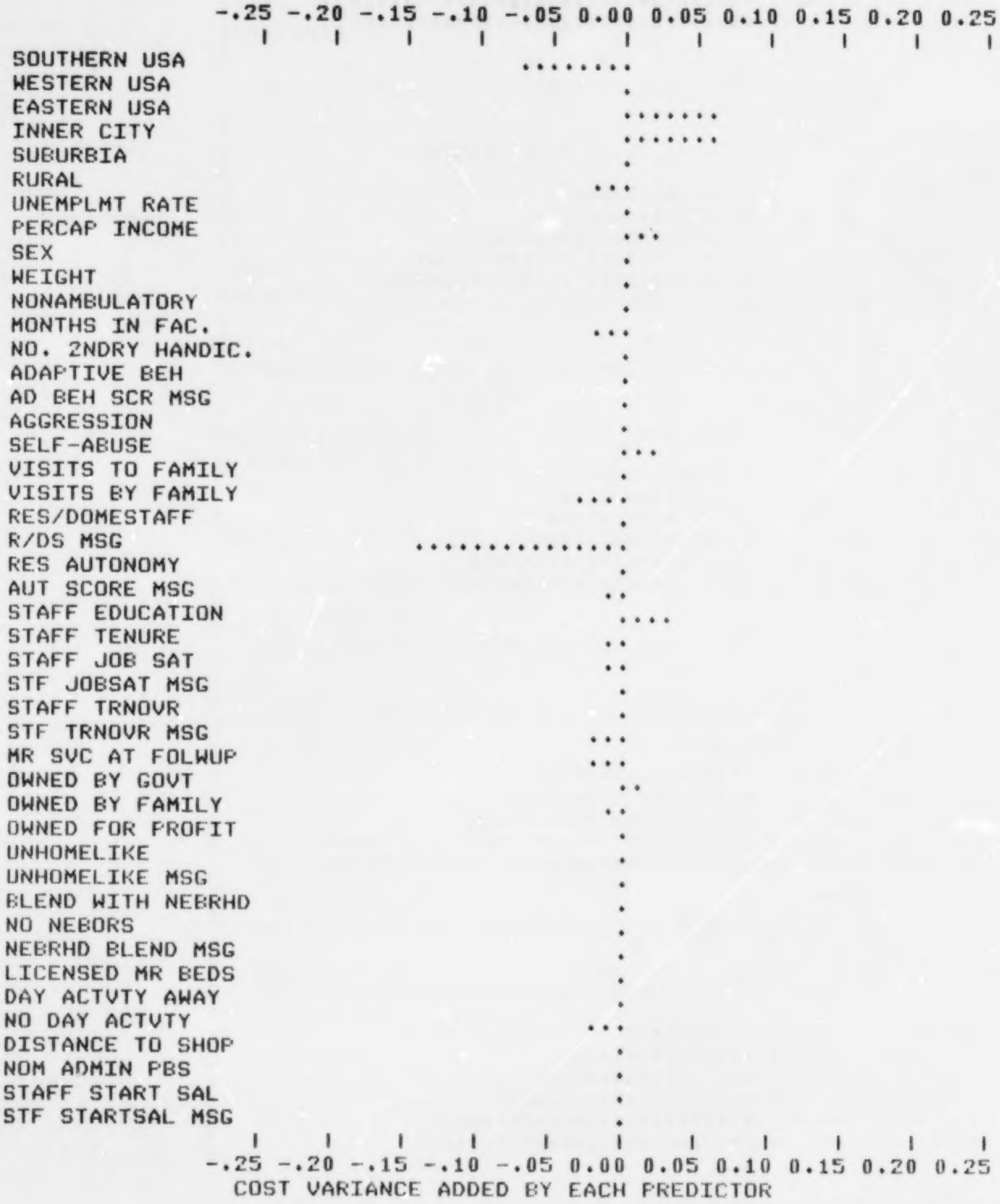


Table 12

```
          CRF WITH 16 OR MORE RESIDENTS

               -.25 -.20 -.15 -.10 -.05 0.00 0.05 0.10 0.15 0.20 0.25
                  |    |    |    |    |    |    |    |    |    |    |
SOUTHERN USA                              oo
WESTERN USA                                o
EASTERN USA                                oo
INNER CITY                                 oooooooooooooo
SUBURBIA                                   o
RURAL                                 oooooo
UNEMPLMT RATE                         oooooo
PERCAP INCOME                              oo
SEX                                        o
WEIGHT                                     o
NONAMBULATORY                              ooo
MONTHS IN FAC.                             o
NO. 2NDRY HANDIC.                          ooo
ADAPTIVE BEH                               o
AD BEH SCR MSG                             o
AGGRESSION                                 o
SELF-ABUSE                                 o
VISITS TO FAMILY                           o
VISITS BY FAMILY                           o
RES/DOMESTAFF                       oooooooo
R/DS MSG                              oooooo
RES AUTONOMY                               o
AUT SCORE MSG                              o
STAFF EDUCATION                            oo
STAFF TENURE                               o
STAFF JOB SAT                              o
STF JOBSAT MSG                             o
STAFF TRNOVR                               o
STF TRNOVR MSG                        oooooo
MR SVC AT FOLWUP                           o
OWNED BY GOVT                              o
OWNED BY FAMILY                            o
OWNED FOR PROFIT                           o
UNHOMELIKE                                 o
UNHOMELIKE MSG                             o
BLEND WITH NEBRHD                          o
NO NEBORS                                  o
NEBRHD BLEND MSG                           o
LICENSED MR BEDS                           oooo
DAY ACTVTY AWAY                            o
NO DAY ACTVTY                              o
DISTANCE TO SHOP                           o
NOM ADMIN PBS                              o
STAFF START SAL                          ooo
STF STARTSAL MSG                           o
                  |    |    |    |    |    |    |    |    |    |    |
               -.25 -.20 -.15 -.10 -.05 0.00 0.05 0.10 0.15 0.20 0.25
                 COST VARIANCE ADDED BY EACH PREDICTOR
```

Table 13

PUBLIC RESIDENTIAL FACILITY

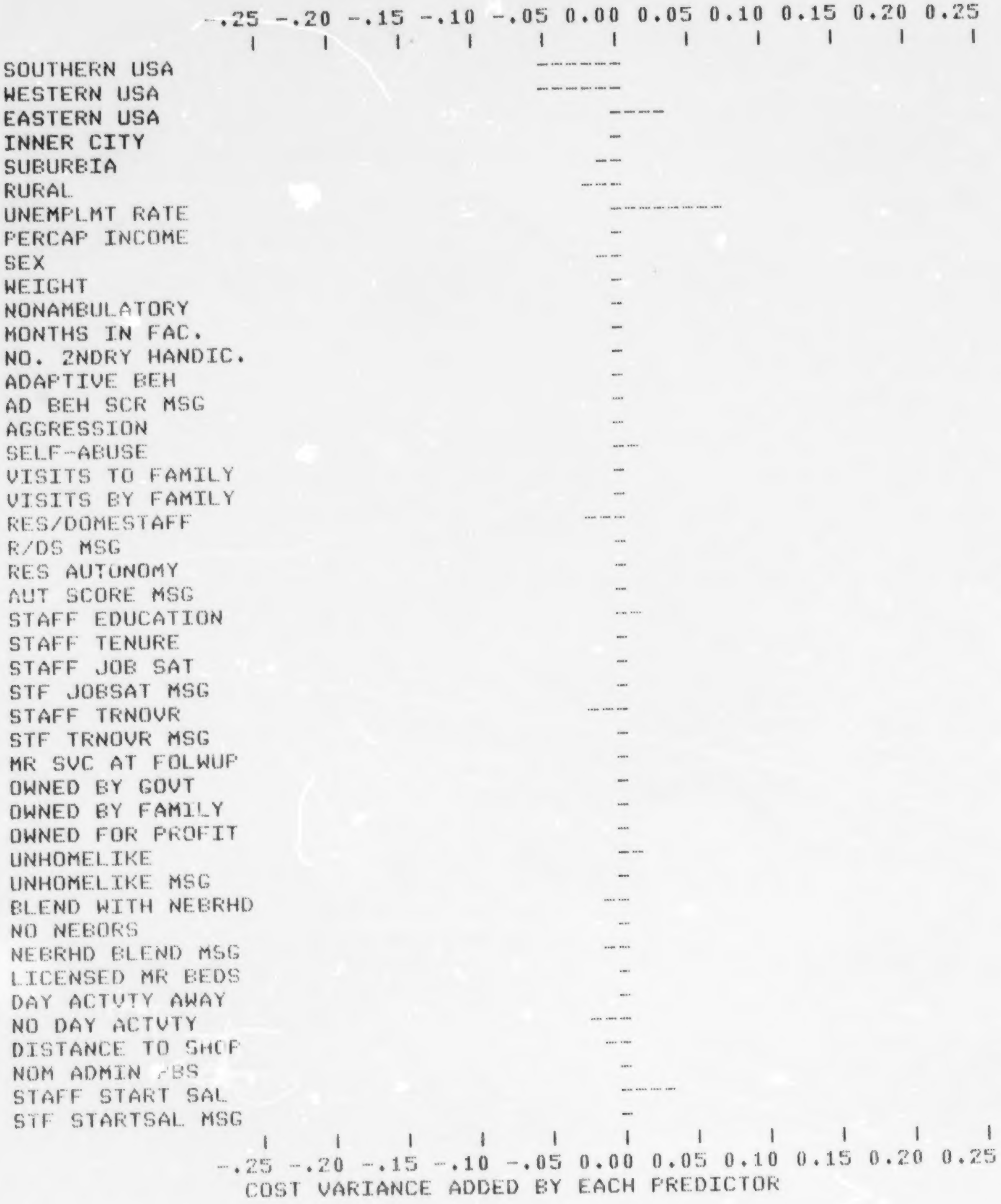


Table 14

NEW ADMISSIONS AND READMISSIONS TO CRFS

```
              -.25 -.20 -.15 -.10 -.05 0.00 0.05 0.10 0.15 0.20 0.25
                 |    |    |    |    |    |    |    |    |    |    |
SOUTHERN USA                              +
WESTERN USA                               +
EASTERN USA                               +++
INNER CITY                                +++
SUBURBIA                                  +
RURAL                                     +
UNEMPLMT RATE                             +
PERCAP INCOME                             +
SEX                                       +
WEIGHT                      +++++++++++++++
NONAMBULATORY                             ++++
MONTHS IN FAC.                            +
NO. 2NDRY HANDIC.                         +
ADAPTIVE BEH                       ++++++++
AD BEH SCR MSG                            +
AGGRESSION                                +
SELF-ABUSE                                +
VISITS TO FAMILY                          +
VISITS BY FAMILY                          +
RES/DOMESTAFF                           +++
R/DS MSG                              +++++
RES AUTONOMY                              +
AUT SCORE MSG                             +
STAFF EDUCATION                           ++
STAFF TENURE                              ++
STAFF JOB SAT                             +
STF JOBSAT MSG                            +
STAFF TRNOVR                             ++
STF TRNOVR MSG                          +++
MR SVC AT FOLWUP                          +
OWNED BY GOVT                             ++++
OWNED BY FAMILY                           +
OWNED FOR PROFIT                          +
UNHOMELIKE                                +
UNHOMELIKE MSG                            +
BLEND WITH NEBRHD                         +
NO NEBORS                                 +
NEBRHD BLEND MSG                          +
LICENSED MR BEDS                          ++++++
DAY ACTVTY AWAY                           +
NO DAY ACTVTY                             +
DISTANCE TO SHOP                          ++++++++++++
NOM ADMIN PBS                             +
STAFF START SAL                           ++
STF STARTSAL MSG                          +
                 |    |    |    |    |    |    |    |    |    |    |
              -.25 -.20 -.15 -.10 -.05 0.00 0.05 0.10 0.15 0.20 0.25
                COST VARIANCE ADDED BY EACH PREDICTOR
```

Table 15

NEW ADMISSIONS AND READMISSIONS TO PRFS

```
              -.25 -.20 -.15 -.10 -.05 0.00 0.05 0.10 0.15 0.20 0.25
                 |    |    |    |    |    |    |    |    |    |    |
SOUTHERN USA                          XXXXX
WESTERN USA                           XXXXX
EASTERN USA                               XXX
INNER CITY                                XXX
SUBURBIA                                  X
RURAL                                    XX
UNEMPLMT RATE                             XXXX
PERCAP INCOME                             XXX
SEX                                       X
WEIGHT                                    X
NONAMBULATORY                             X
MONTHS IN FAC.                            X
NO. 2NDRY HANDIC.                         X
ADAPTIVE BEH                          XXXXX
AD BEH SCR MSG                            X
AGGRESSION                                X
SELF-ABUSE                                XX
VISITS TO FAMILY                          XX
VISITS BY FAMILY                          X
RES/DOMESTAFF                         XXXXX
R/DS MSG                                 XX
RES AUTONOMY                              X
AUT SCORE MSG                             X
STAFF EDUCATION                           XXXXX
STAFF TENURE                              X
STAFF JOB SAT                             X
STF JOBSAT MSG                            X
STAFF TRNOVR                             XX
STF TRNOVR MSG                            XX
MR SVC AT FOLWUP                          X
OWNED BY GOVT                             X
OWNED BY FAMILY                           X
OWNED FOR PROFIT                          X
UNHOMELIKE                                X
UNHOMELIKE MSG                            X
BLEND WITH NEBRHD                        XX
NO NEBORS                                 X
NEBRHD BLEND MSG                          X
LICENSED MR BEDS                        XXX
DAY ACTVTY AWAY                           X
NO DAY ACTVTY                           XXX
DISTANCE TO SHOP                         XX
NOM ADMIN PBS                           XXX
STAFF START SAL                           XXXX
STF STARTSAL MSG                          X
                 |    |    |    |    |    |    |    |    |    |    |
              -.25 -.20 -.15 -.10 -.05 0.00 0.05 0.10 0.15 0.20 0.25
                COST VARIANCE ADDED BY EACH PREDICTOR
```

COST FUNCTION ANALYSIS OF MINNESOTA INTERMEDIATE CARE FACILITIES FOR MENTALLY RETARDED

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State Planning Agency
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Introduction

The direction of deinstitutionalization may be determined in the future by costs, at both the national and state levels. Cuts in federal programs and state budget difficulties have made cost analyses imperative. Cost is becoming a central issue in both providing existing programs and developing new services. Identifying factors in the cost of programs will enable policy-makers and service providers to plan more effectively and use resources more efficiently; it will also enable them to assess more accurately the relative merits of alternative models of service delivery.

The importance of cost implications in community-based services for developmentally disabled people in Minnesota is underscored by several factors. Among these, the Welsch v. Noot Consent Decree (1980) to further reduce the number of mentally retarded people living in state institutions; the continuing increase in the number of community-based intermediate care facilities for the mentally retarded (ICF-MRs); the "double-funding" dilemma of maintaining both a state hospital and a community-based system of services; and the emergence of alternative, cost-efficient models of residential care such as specialized adult foster care, semi-independent living services, and family subsidy and support programs.

This paper presents the findings of three studies of Minnesota community-based ICF-MR per diem costs. The primary purpose of these studies was to identify the critical factors (separately and in combination) which produce variations in per diem costs in ICF-MRs. The population frame included all ICF-MRs in Minnesota for which reliable data were available for 1979 (N = 185), 1980 (N = 230), and 1981 (N = 261).

ICF-MR Facilities in Minnesota

Since the early 1960s, Minnesota has gradually increased the capacity of its community-based residential care system. Twenty years ago there were approximately 100 people living in Minnesota's five group homes. In 1981, there were 281 community-based ICF-MRs in the state, with a total licensed capacity of 4,669. While the largest number of facilities had 6 residents or less, this group of facilities accounted for only 11.8 per cent of the state's total community ICF-MR capacity. Conversely, the 9 largest facilities represented only 3.7 per cent of the total number of facilities in

1981, but accounted for nearly 1 out of 4 community ICF-MR beds. Table 1 shows the distribution of ICF-MRs operating in 1981 by licensed capacity.

Table 1

Number and Licensed Capacity of Minnesota ICF-MRs by Size Category: 1981

SIZE OF FACILITY	FACILITIES		LICENSED CAPACITY	
	Number	Per cent	Total	Per cent
6 or fewer residents	92	32.7%	551	11.8%
7 to 12 residents	86	30.6	832	17.8
13 to 16 residents	61	21.7	899	19.3
17 to 32 residents	10	3.6	271	5.8
33 to 64 residents	21	7.5	985	21.1
65 or more residents	11	3.9	1,131	24.2
TOTAL	281	100.0%	4,669	100.0%

Methodology

The statistical methodology employed in these studies is a replication of the cost-function analysis of a national study on the costs of residential care (Wieck and Bruininks, 1980). That report contains a thorough review of literature of previous cost studies and a discussion of the "theory" which underlies these studies' treatment of cost-related variables.

The data for the studies came from two primary sources: Department of Public Welfare (DPW) Rule 52 cost reports on file in the Long-Term Care Rate Division; and the data files of the Quality Assurance and Review Program within the Department of Health.

DPW Rule 52 establishes the standards for determining reimbursement (per diem) rates for providers of ICF-MR residential services. Providers must submit a cost report each year. The per diem rate for each facility is based upon actual, allowable expenses incurred during the preceding year plus any allowable known cost changes which will occur during the upcoming year.

The Quality Assurance and Review (QAR) program is a federal program which annually surveys facilities reimbursed under the federal Medicaid program. QAR surveys report on resident dependency, potential for restoration, and treatment programs. They also indicate the appropriateness of current placements and the potential for movement into less restrictive living arrangements.

In these studies, cost factors were defined according to three categories: location, organizational structure, and resident characteristics. The studies examine a number of variables and their impact upon cost using two statistical techniques: analysis of variance and multiple regression.

Analysis of Variance

The first objective of the studies is to test hypotheses about relationships between selected variables, such as facility size or resident characteristics, and per diem rates (cost). Through a comparison of mean values, one-way analysis of variance determines differences in facility per diem rates; and then whether or not those differences are significant enough statistically to allow certain assumptions about cost-influencing variables. The hypotheses and results of these analyses are summarized below.

A. Locational Factors

Two locational factors were examined in these studies: location in 1 of Minnesota's 13 economic development regions, and urban/non-urban location. The one-way analysis of variance tests revealed the following results when per diem rates were examined:

1. Region

In each of the three studies, there were significant differences ($p < .01$) in the per diems of ICF-MRs located in Minnesota's 13 economic development regions. The highest average per diems were found in the Minneapolis-St. Paul region.

2. Urban/Non-urban Location

According to data provided by the Census Bureau for 1982, there were seven major urban areas in Minnesota: Duluth, Moorhead, East Grand Forks, LaCrescent, Rochester, St. Cloud, and Minneapolis-St. Paul.

The national study of group home per diems (Wieck and Bruininks, 1980) indicated that there were no significant differences between per diems of metropolitan facilities and facilities located outside of a metropolitan area. Each of the current studies indicated, however, that there were significant differences ($p < .01$) between facilities located in urban areas and those outside of urban settings. For

1981, facilities operating in the urban areas had an average per diem of $54.30, which was 20 per cent higher than the average $45.20 per diem for non-urban locations.

B. Organizational Factors

Eight organizational factors were examined in these studies for their probable impact upon per diem rates: (1) facility size, (2) licensed capacity, (3) occupancy rate, (4) staff-resident ratios, (5) profit/non-profit status, (6) system affiliation, (7) type of license, and (8) years of operation. The one-way analysis of variance tests revealed the following results when per diem rates were examined:

1. Size

For the purpose of these studies, size is the actual number of clients present in the facility over the course of the year. "Size" is very similar to "licensed capacity" because most ICF-MRs in Minnesota operate near or at capacity.

Facilities were grouped into six categories: 6 or fewer residents, 7 to 12 residents, 13 to 16 residents, 17 to 32 residents, 33 to 64 residents, and 65 or more residents.

There were significant differences ($p < .01$) in the per diem rates according to these size categories. The highest per diems were found among larger ICF-MRs which served 17 or more people and those facilities serving 6 or fewer residents, which are typically newer facilities. The lowest per diem was found in very large facilities (more than 64 beds), which were typically older facilities.

The higher costs for facilities between 17 and 64 resident size may be attributed in part to increasing staff requirements and, hence, direct care staff. The higher costs for facilities serving fewer than 6 residents in size may be due in part to their high start-up costs.

2. Licensed Capacity

Since ICF-MRs typically operate at or near licensed capacity (98 per cent occupancy), the results of the one-way analysis of variance were similar to the results when categorized by size (number of residents). There was a significant difference ($p < .01$) in per diem rates according to the categories of facilities by licensed capacity. The trends again indicate higher per diem rates for smaller facilities, decreasing per diem rates in midsize facilities, and increasing per diem rates for larger facilities, except for the extremely large facilities (64 bed or larger).

3. Occupancy Rate

Occupancy rate was defined as the number of residents divided by the licensed capacity. Occupancy ranged from less than 80 per cent to 100 per cent. The rates were categorized as follows: 80 per cent or less, 81 to 90 per cent, 91 to 95 per cent, and 96 to 100 per cent.

Previous studies have suggested that variation in occupancy rates had important consequences for cost, primarily because per diem is calculated on the number of residents (Peat, Marwick, Mitchell, and Co., 1976; Piasecki, Pittinger, and Rutman, 1977).

However, the one-way analyses of variance did not reveal any significant differences when groups of facilities were compared by occupancy rate, primarily because in Minnesota ICF-MRs operate at similar rates of resident occupancy; 98 per cent is the statewide average.

4. Staff-Resident Ratio

The staff-resident ratio is calculated by dividing the number of direct care staff (full-time equivalent) by the number of residents (size).

Previous studies have indicated that per diem rates (cost) are greatly influenced by personnel costs. The number and type of staff are greatly influenced, in turn, by several factors which make it hard to identify precisely the relationship. Some of those factors are resident characteristics, functioning levels, types of services provided and regulatory standards for staffing.

In these studies, facilities were grouped according to five categories based upon staff-resident ratios: less than 0.30; 0.30 to 0.49; 0.50 to 0.69; 0.70 to 0.99; and greater than 1.00.

There were significant differences ($p < .01$) when facilities were compared by categories of staff-resident ratios. Facilities with the lowest staff-resident ratio (less than 0.30) had the lowest average per diem. As staff-resident ratios increased, average per diems increased. The highest average per diem was associated with facilities having a staff-resident ratio greater than 0.99.

5. Proprietary Status

The analyses did not reveal any significant differences between facilities compared by profit/non-profit status. The mean average per diem for non-profit facilities was slightly higher than for profit facilities ($49.90 versus $49.10 in 1981).

6. Membership in a System

For the purpose of these studies, a facility was identified as a member of a system if the organization which owned the home also owned at least one other ICF-MR facility in Minnesota. A facility which was owned by an organization with other nursing or boarding homes or out-of-state facilities was not considered a member of a system.

No significant differences were found when comparing per diem rates of facilities which were members of a system and those that were not at the $p < .01$ level. However, at the $.01 < p < .05$ level, facilities which were members of a system were statistically different than those facilities which were not. In 1981, facilities which were system members had an average per diem of $50.60, while the average per diem for non-system facilities was $45.70. Over 72 per cent of all facilities were members of a system. The number of beds within an individual system ranged from 12 to 506.

7. Class A/Class B Licensure

ICF-MRs in Minnesota are licensed as either Class A or Class B depending upon the mobility and self-preservation skills of the residents (their ability to evacuate the building during an emergency). Class B facilities are for people who would not be able to do so. A Class B license may require certain structural accommodations or staffing.

The results of one-way analysis of variance tests indicated statistically significant differences ($p < .01$) between Class A and Class B facilities. In 1981, Class B facilities had an average per diem of $67.20, nearly 44 per cent higher than the Class A facilities' $46.80 average. Further analysis indicated that this difference may be due in part to client characteristics, staffing, and regulations regarding building structure.

8. Years of Operation

As previous studies in this area indicate (Piasecki et al., 1978), newer or recently-opened facilities have larger per diem costs due to increased start-up costs.

Years of operation were calculated by subtracting the year and month in which the facility was first licensed by the Department of Public Welfare from the year and month at 1981 fiscal year end. The years of operation were categorized into five groups: less than 1.0 years; 1.1 to 3.0 years; 3.1 to 5.0 years; 5.1 to 8.0 years; and longer than 8.0 years.

The one-way analysis of variance indicated statistically significant differences ($p < .01$) for facility per diem rates by years of operation. There is an inverse relationship between per diem rates and years of operation. The highest average per diem was associated with those facilities opened recently (less than 1.0 year) and fairly recent (1.0 to 3.0 years ago). The lowest average per diem was found in facilities operating for more than 8 years.

C. Resident Factors

Six variables related to resident characteristics or functioning were compared against per diem rates: (1) average age of residents; (2) percentage of residents who are severely or profoundly mentally retarded; (3) percentage of residents who are completely fed; (4) percentage of residents with behavior problems; (5) percentage of residents who are not toilet trained; and (6) percentage of clients who are non-ambulatory. A greater level of resident dependency suggests a need for more direct care services, increasing staff ratios, and consequently increasing costs. According to 1981 QAR data, 14 facilities (all Class B) accounted for nearly all the residents who are reported to have higher levels of dependency in the areas of feeding and ambulation.

The results of the one-way analyses of variance are as follows:

1. Age of Residents

For these studies, five age groups were defined: less than 16 years; 16 to 25 years; 26 to 35 years; 36 to 45 years; and older than 45 years.

Statistically significant differences ($p < .01$) occurred when facilities were compared by the average age of the residents served. An inverse relationship was present between average age of residents and per diem rates. The highest average per diems were associated with facilities serving residents less than 16 years of age. The lowest average per diem was found at those facilities serving residents who averaged 45 years of age or older.

2. Proportion of Residents Severely or Profoundly Mentally Retarded

The proportion of residents who were classified as severely or profoundly mentally retarded were categorized into seven groups: 0 to 5 per cent; 6 to 9 per cent; 10 to 19 per cent; 20 to 39 per cent; 40 to 49 per cent; 50 to 74 per cent; and 75 to 100 per cent.

The one-way analyses of variance indicated statistically significant differences ($p < .01$) when facility per diems were compared according to the proportion of residents classified as severely or profoundly mentally retarded. The highest average per diem costs were reported by those facilities serving more than 75 per cent residents who were severely or profoundly retarded. Facilities with 6 to 9 per cent of their residents severely or profoundly mentally retarded had the lowest average per diem costs.

3. Proportion of Residents Who Are Completely Fed

Facilities were categorized according to the proportion of residents who must be completely fed. Most facilities (95 per cent in 1981) reported that 6 per cent or fewer of the residents required complete feeding. The results of the one-way analyses indicated significant differences (p .01). The five facilities with dependency levels of 40 per cent or more had the highest average per diem, at $92.90 in 1981.

4. Proportion of Residents with Behavior Problems

Facilities were classified into five groups according to the proportion of residents who were reported to have severe behavior problems (defined as "disturbs others, runs away, is verbally aggressive, threatens, steals, is destructive, is assaultive or self-injurious").

Significant differences ($p < .01$) were indicated by the one-way analysis of variance tests. Facilities reporting that more than 50 per cent of the residents had severe behavior problems had the highest per diems, while those facilities having 5 per cent or less of their residents with severe behavior problems had the lowest per diems.

5. Proportion of Residents Not Toilet Trained

Facilities were categorized according to the proportion of residents who were not toilet trained. The results of the one-way analyses indicated significant differences (p .01). The highest average per diems were associated with those facilities in which more than 25 per cent of the residents were not toilet trained.

6. Proportion of Residents Non-ambulatory

Department of Health QAR data were used to group facilities according to the proportion of residents who were non-ambulatory: less than 10 per cent; 10 to 19 per cent; 20 to 39 per cent; and more than 39 per cent. Over 95 per cent of the facilities reported low proportions of non-ambulatory residents. The results of the one-way analysis tests indicated significant differences ($p < .01$). The highest mean per diem rates were for facilities with more than 39 per cent non-ambulatory residents, and the lowest mean per diems were for facilities with 9 per cent or less non-ambulatory residents.

Cost-Function Analysis

The first portion of these studies used a statistical technique called one-way analysis of variance, which defined groups of facilities according to selected variables and compared mean per diems of groups based only upon those single factors. Cost factors, however, are often interrelated; and two or more variables acting together may influence the cost of residential care services.

The second objective of these studies was to explain cost relationships using a cost-function approach. A cost-function is the testing of statistical relationships between independent variables, such as facility location or staff-resident ratios, and cost (the dependent variable) using multiple regression techniques. Multiple regression makes it possible to evaluate the influence specific variables may have upon cost, while at the same time accounting for the possible impact of several other variables.

The dependent variable in these analyses was per diem rate. Additional variables were included in the 1981 analysis, with a total of 25 independent variables used to predict cost. The results of the 1981 analysis are as follows:

The regression analysis indicated that 15 of the 25 variables were statistically significant predictors of per diem cost. Thirteen variables were significant at $p < .01$ level: location; number of direct care staff (full-time equivalent); staff-resident ratio; property and related costs; general and administrative cost; earnings allowance; resident behavior problems; percentage of residents not toilet trained; Class A or Class B licensure; and, inversely related: size; fixed cost ratio; return on investment ratio; and years of operation. The variables of proprietary status and average age of residents (inversely related) were significant at $p < .10$ level. The overall regression equation accounted for 92.2 per cent of the variance in per diem costs.

In a second analysis, facilities were divided into two groups: (1) facilities serving 12 or fewer residents and (2) facilities serving more than 12 residents. A regression analysis was then performed on each of these groups.

The regression equation for facilities serving 12 or fewer clients (N - 167) indicated that 10 of the 25 variables were statistically significant predictors of per diem costs. Seven variables were statistically significant at the $p < .01$ level: location; proprietary status; number of direct care staff (full-time equivalent); property and related costs; general and administrative costs; earnings allowance; and fixed cost ratio (inversely related). One variable was significant at the $p \angle .05$ level and two variables at the $p < .10$ level. These variables, respectively, were average age of residents (inversely related), occupancy rate, and years of operation (inversely related). This regression equation explained 91.5 per cent of the variance in per diems.

In the regression analysis for facilities serving more than 12 residents (ranging from 13 to 171 residents with N - 94), the equation explained 95.2 per cent of the 95.2 per cent of the variance in per diem costs. Fourteen of the 25 variables were statistically significant. Ten variables were significant at the p < .01 level: size (inversely related); direct care staff (full-time equivalent); staff-resident ratio; interest expense on working capital loans (inversely related); property and related costs; general and administrative costs; earnings allowance; fixed cost ratio (inversely related); consultant/contract expenses; and years of operation (inversely related). Three variables were statistically significant at the p < .05 level: location; percentage of residents not toilet trained; and Class A or Class B licensure. One variable was statistically significant at p < .10 level: resident behavior problems.

Table 2 summarizes the significant variables identified by the regression analyses and their relationship with per diem ratio.

Policy Issues

The data presented in these studies are not definitive, but statistical presentations of information derived from ICF-MR cost reports and Health Department records. The data are presented to help define problems, clarify trends, and outline some basic issues regarding community residential care services. Although cost remains a major consideration as both the state and federal governments struggle with substantial budget deficits, it is not the only consideration. Normalization, appropriateness of services, and the movement of developmentally disabled people into less restrictive living arrangements must also remain high priorities.

A. The Role of ICF-MRs

These studies focused on ICF-MR residential services. While other states chose to maintain ICF-MR certification for medically-oriented services, Minnesota became one of the first states to develop smaller, community-based ICF-MRs as an alternative to institutional care. Consequently, the number of community ICF-MR certified beds in Minnesota has increased substantially since the mid-1970s. Programs and finances now dictate that expansion of the system should occur only after a thoughtful analysis of the need for more ICF-MR capacity, a review of the role of ICF-MR services, and an examination of alternative care models. These analyses should consider several factors.

B. Long-Term Financial Implications

Like state institutions, ICF-MR represent major capital investments. The nature and extent of those investments are reflected in DPW Rule 52 reimbursement standards. Substantial amounts of federal, state, and county resources are tied to the

Table 2
Summary of Regression Results: Significant Variables

Regression Analysis	Significant Variable	P Level	Relationship to per Diem
Overall:	Location	.01	positive
	Proprietary Status	.10	positive
N = 261	Size	.01	inverse
R^2 = 92.2	Direct Care Staff (FTE)*	.01	positive
	Staff-Resident Ratio	.01	positive
	Property and Related Costs	.01	positive
	General and Administrative Costs	.01	positive
	Earnings Allowance	.01	positive
	Fixed Cost Ratio	.01	inverse
	Return on Investment Ratio	.01	inverse
	Years of Operation	.01	inverse
	Average Age of Residents	.10	inverse
	Behavior Problems	.01	positive
	Percentage of Residents Not Toilet Trained	.01	positive
	Class A or Class B Licensures	.01	positive
Facilities Serving 12 or Fewer Residents:	Location	.01	positive
	Proprietary Status	.01	positive
	Occupancy Rate	.10	positive
N = 167	Direct Care Staff (FTE)	.01	positive
R^2 = 91.5	Property and Related Costs	.01	positive
	General and Administrative Costs	.01	positive
	Earnings Allowance	.01	positive
	Fixed Cost Ratio	.01	inverse
	Years of Operation	.10	inverse
	Average Age of Residents	.05	inverse
Facilities Serving 13 or More Residents:	Location	.05	positive
	Size	.01	inverse
	Direct Care Staff (FTE)	.01	positive
N = 94	Staff-Resident Ratio	.01	positive
N^2 = 95.2	Interest on Working Capital Loans	.01	inverse
	Property and Related Costs	.01	positive
	General and Administrative Costs	.01	positive
	Earnings Allowance	.01	positive
	Fixed Cost Ratio	.01	inverse
	Consultant/Contract Expenses	.01	positive
	Years of Operation	.01	inverse
	Behavior Problems	.10	positive
	Percentage of Residents Not Toilet Trained	.05	positive
	Class A or Class B Licensure	.05	positive

*FTE = Full-Time Equivalent.

construction and maintenance of physical structures. The long-term implications of those types of financial commitments need to be explored fully.

C. Meeting Individuals' Needs

Reliance on construction or maintenance of an already existing service may inadvertantly direct public resources to meet the needs of bricks and mortar rather than of people. To respond to an ever-changing group of clients, the service system must adapt and be capable of change. ICF-MR facilities should be viewed as one type of service within a broad array of programs and services available to people with developmental disabilities. Those services should remain flexible and promote, wherever possible, movement into more independent, and usually less costly, settings. To achieve those ends, funding should accommodate people, not programs.

D. Meeting Demands for Service

Much of the demand for community placements could be met by existing ICF-MRs if appropriate alternative services for many current ICF-MR residents were developed and adequately funded. For many people, ICF-MR services may be the most appropriate service model; for others, they may represent only one step in growth and change. QAR data suggest that as many as 200 people now living in group homes are ready to move into semi-independent living settings; other estimates indicate that, with varying levels of supervision, as many as 1,000 people could be placed into foster care or semi-independent living services.

E. Size of Community Facilities

Size of facilities remains an issue. The current study indicates that the smallest facilities are not the least costly. Several mitigating factors should be considered, however. Most of the smallest ICF-MRs are relatively new facilities. Inflation and the recent increases in costs of construction and financing may account for much of the cost difference. As well, people now placed into community facilities are more likely to have lower levels of functioning or physical handicaps than people placed several years ago in older facilities. Higher resident dependency suggests higher staff-resident ratios, and increased costs. Finally, the literature suggests that when all factors are considered, the psycho-social and developmental needs of individual residents are better met in small, homelike residential programs than in larger facilities.

F. Larger Community Facilities

The appropriateness of larger community ICF-MRs also needs to be addressed. In 1980, the ten largest facilities accounted for nearly one quarter of the total community ICF-MR bed capacity. Some facilities exceed the size of state hospital programs. In 1980, nearly half (49 per cent) of the people in community-based ICF-MRs lived in "group homes" with more than 32 residents.

G. Less Costly Alternatives

Community ICF-MR programs are not cheap. In fact, the costs of community placement for a former state hospital resident may approach those of the state hospital system, when costs of day programming and support services are included. This is most true for children. Residential and day programs for children are relatively more expensive than adult programs. Consideration should be given to developing in-home support services and expanding family subsidies. Not only are these programs more cost-efficient, but they may help to forestall or alleviate the need for placements into costly institutional and ICF-MR settings.

H. Meeting Policy Objectives and Providing Quality Services

Budget deficits and demands for cost containment have resulted in caps on reimbursement rates and, more recently, reductions in payments to providers. Moving people into semi-independent living services and developing appropriate alternative services, such as adult foster care, may result in cost savings. Many alternative care models are both compatible with cost considerations and consistent with policies which promote normalization and less restrictive living environments.

I. Support Services

The further development of ICF-MR programs, as well as other community-based residential care programs, cannot proceed without considering the availability and appropriateness of community support services. There are two major areas of concern: (1) the availability of day programs and (2) adequate case management services.

J. Adequate and Appropriate Day Programs

The ultimate success of residential care services is dependent upon the availability of appropriate day programs committed and geared toward client development in self-help skills, academics, vocational skills, and meaningful employment. Current opportunities are limited. Data indicate that many potential clients are waiting to participate in developmental achievement center programs. At the same time, current DAC participants are ready to move into sheltered workshops but are unable to make that transition because there are no vacancies (Policy Analysis Paper No. 8, 1982). Future development of community residential programs must be closely tied to the availability of quality day programs capable of meeting the residents' needs.

K. Decentralized Services and Quality Control

The success of community programs is also dependent upon an adequate supply of case management services. In a system of care which is becoming more and more decentralized, it is imperative to have a workable case management system (reasonable caseloads) which can help ensure that appropriate programs and services are available, that necessary services are provided, and that quality of programs is maintained. Few places in Minnesota have adequate case management services.

L. ICF-MR Services in Minnesota

The community-based ICF-MR is an important component of Minnesota's system of care for developmentally disabled people. Program and budgetary circumstances, however, will require policymakers to reassess the role of the ICF-MR and plan its further development. Those analyses cannot take place without considering other aspects of the community-based care system: day programming, funding mechanisms, adequate monitoring, and less costly alternative services. The result should be an even more dynamic array of services which is responsive to the individual needs of developmentally disabled people in Minnesota.

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Developmental Disabilities Program. **Policy analysis paper no. 4: Cost function analysis of Minnesota intermediate care facilities for mentally retarded (ICF-MR) per diems.** St. Paul: Developmental Disabilities Program; Department of Energy, Planning and Development; September 1981.

Developmental Disabilities Program. **Policy analysis paper no. 15: An update to policy analysis paper no. 4: Cost function analysis of Minnesota intermediate care facilities for mentally retarded (ICF-MR) per diems: 1980.** St. Paul: Developmental Disabilities Program; Department of Energy, Planning and Development; March 14, 1983.

Developmental Disabilities Program. **Policy analysis paper no. 19: An update to policy analysis papers no. 4 and 15: Cost function analysis of Minnesota intermediate care facilities for mentally retarded (ICF-MR) per diems: 1980 and 1981.** St. Paul: Developmental Disabilities Program, State Planning Agency, August 14, 1983.

Several staff members prepared these reports, including: Scott Nagel, Dave Theisen, Michelle Casey and Audrey Clasemann.

PART THREE

EFFECTS

ASSESSING THE EFFECTIVENESS OF DEINSTITUTIONALIZATION: SUBSTANTIVE AND METHODOLOGICAL CONCLUSIONS FROM THE RESEARCH LITERATURE

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In preparing this paper, I was responding to an invitation from Dr. Harry MacKay of the Canadian Council on Social Development to discuss the methodologies used and technical problems encountered in evaluations of the effectiveness of deinstitutionalization programs. The paper has four major sections.

First, it deals with several preliminary issues: the definition of the term "deinstitutionalization"; the implications for the CCSD study of the World Health Organization (1980) model of impairment, disability, and handicap; possible outcome levels and domains; and the extent and distribution of disability in Canada.

Second, the research literature on deinstitutionalization is reviewed in three fields: mental health, mental retardation, and physical disability. Implications are drawn for the CCSD study.

Third, it summarizes the results of a recent analysis of a large sample of service program evaluations carried out with PASS 3 (Program Analysis of Service Systems, 3rd edition, Wolfensberger & Glenn, 1975), for two reasons. The findings bear on the question of the comparative quality of community and institutional services. Methodologically, they illustrate that PASS, unlike many tools which tend to be field-specific or clientele-specific, applies to the various populations of interest in the CCSD research (the psyachiatrically, intellectually, and physically disabled) as well as to the different types of programs that require evaluation (institutional and community services, whether residential, vocational, educational, or recreational in nature).

Fourth, a number of suggestions are made for the planning and conduct of the CCSD study, based on the preceding sections as well as on my participation in the symposium itself.

Preliminary Considerations

DEINSTITUTIONALIZATION

"Deinstitutionalization" has become a term of abuse, a synonym for the dumping of clients into board and care homes without supports and safeguards (see, for example, Noble & Conley, 1981). Here, however, I use the term in a different and positive sense, as defined by the National Institute of Mental Health in the U.S.:

1) the prevention of inappropriate mental hospital admissions through the provision of community alternatives for treatment;

2) the release to the community of all institutionalized patients who have been given adequate preparation for such a change; and

3) the establishment and maintenance of community support systems for non-institutionalized people receiving mental health services in the community. (cited in Braun et al., 1981, p. 739)

I regard "deinstitutionalization" in this sense as a very desirable goal, consistent with, although less ambitious than, either "normalization" ("the use of culturally normative, and optimally even culturally valued, means to enable persons to achieve and maintain valued social roles"; Wolfensberger & Thomas, 1983, p. 18) or "rehabilitation" ("restoration not only of function but also to valued social status and social role"; Flynn, 1984, p.7). It will be essential for the CCSD and the study Working Group to provide a clear definition of the nature, goals, and boundaries of the central phenomenon whose costs and effects are to be evaluated.

IMPAIRMENT, DISABILITY, AND HANDICAP

Like "deinstitutionalization", the terms "impairment", "disability", and "handicap" must also be given clear conceptual definitions before they can be translated into operation. For present purposes, I am using them in the same sense as the World Health Organization (WHO, 1980) defines them. According to the WHO model, impairment, disability, and handicap are all consequences of disease (Figure 1).

Figure 1

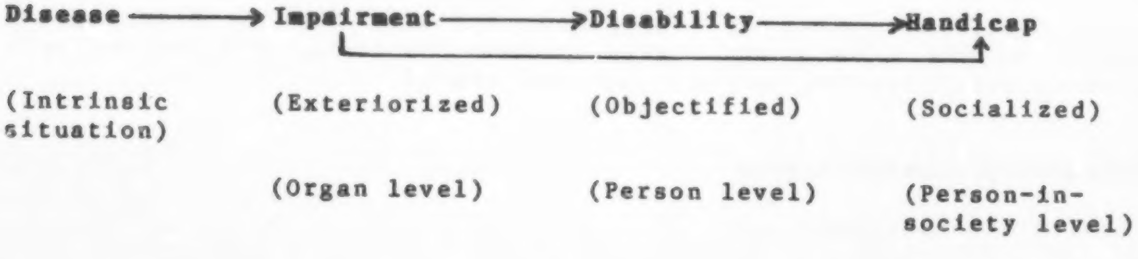

Figure 1. Model of impairment, disability, and handicap as consequences of disease (World Health Organization, 1980).

"Disease" (or better, "condition" or "disorder") is simply something abnormal occurring within the individual, either present at birth or acquired. In this very general sense (going beyond the confines of the medically-oriented WHO schema), the physical, intellectual, or psychological "disease" (disorder) may be as much the result of a depriving environment or of faulty learning as of wayward biochemistry or genes. Moreover, it is chronic rather than acute diseases (conditions) that produce long-term phsycial, psychological, or social consequences.

"Impairment"' the direct consequence of "disease", is any loss or abnormality of psychological, physiological, or anatomical function. The person and others become aware of the impairment and recognize that an internal disease, condition, or disorder exists. Impairments are disturbances in the organs, whether or not active disease is still present.

"Disability" is any restriction, resulting from an impairment, in a person's ability to perform an activity in the manner or within the range considered normal for a human being. Objectification takes place, in that the person's behaviour may be altered as a result of the impairment or the person's awareness of it. Common, ordinary activities may become restricted, and the individual may acquire psychological reactions to the impairment (depressed mood, "illness behaviours", etc.). Disabilities are disturbances within the person, and reflect the possible -- but not inevitable -- consequences of impairments in terms of functional performance and activity by the individual.

"Handicap", finally, refers to the disadvantage that may result when an impairment or a disability limits the fulfillment of a role that is considered normal (depending on age, sex, and sociocultural factors) for an individual. Handicap is the negative value attached to the person's situation or experience when it departs from the norm. It is characterized by a discordance between the person's performance and the expectations of the individual, and especially of his or her social group. Handicap thus involves socialization of an impairment or disability and realects their negative cultural, social, economic, and environmental consequences.

The foregoing are distinctions that, unlike some, do make a difference. In the CCSD study, it seems to me that most attention should be paid to "handicap" in conceptualizing appropriate services. For deinstitutionalization most fundamentally succeeds to the extent that it reduces the multiple disadvantages (devaluation, residential and social segregation, unemployment, and poverty) that often confront physically, intellectually, or emotionally impaired or disabled people.

At the same time, the WHO (1980) model is a useful reminder that deinstitutionalization programs may, in some instances, have the greatest impact on handicaps by reducing disabilities or impairments. The latter phenomenon also deserves attention in the CCSD study. The WHO (1980) manual should be consulted for further details.

POSSIBLE OUTCOME LEVELS AND DOMAINS

In any deinstitutionalization study, the major outcomes of interest exist on seven levels: that of the individual (including his or her handicaps as well as disabilities and impairments), the family, the program (including staff), the community, the service region, the province, and the nation. No single study, even with unusual resources, can hope to assess effects on more than two or three of these levels. Attention to all seven levels would be possible only for a well-planned, sequential, long-term, national research program on deinstitutionalization, which the CCSD study may help to stimulate.

Priorities may be established among the seven levels by recognizing that outcomes at the higher, more abstract levels will often be determined by the aggregate effects at the lower, more concrete ones. Hence, the individual, family, and program levels represent, in my opinion, the best places to focus the CCSD study.

At the level of the individual, a variety of outcome domains have been proposed in the literature. Backer (1977) sees the core of outcome measurement as changes in clients' vocational, economic, physical, and psychosocial functioning. Anthony (1980) recommends that evaluations include measures of gains in skills the clients need to function in their particular environments, of benefits both to clients and to society (employment, reduced hospitalization, decreased contacts with the police, etc.), of client quality of life (number of hours spent alone per week, number of social contacts, number of new items of clothing per year, etc.), and client satisfaction with services. Schulberg and Bromet (1981) specify social adaptation, psychiatric status, environmental conditions, vocational performance, satisfaction with treatment, and quality of life (a composite of the preceding variables) as their preferred outcomes on the client level.

I believe, as I mentioned previously, that the WHO (1980) schema is a very useful starting point for conceptualizing client-level outcomes, especially handicaps. The model is applicable (at least by analogy) to all forms of disability, whether intellectual, psychological, or physical. Across different disabilities, the same handicaps could be evaluated, whether these are handicaps affecting orientation, physical independence, mobility, occupation, social integration, or economic self-sufficiency (cf. WHO, 1980). Even if more sophisticated measures than the simple scales in the WHO manual are chosen for these handicaps, the use of a single conceptual framework for clients with different impairments or disabilities would, I think, prove advantageous in the CCSD evaluation.

DISABILITY IN CANADA

Although Statistics Canada is beginning to undertake large-scale surveys of the nation's disabled population, the results of this work will not be available for some time. In the meantime,

Figure 2

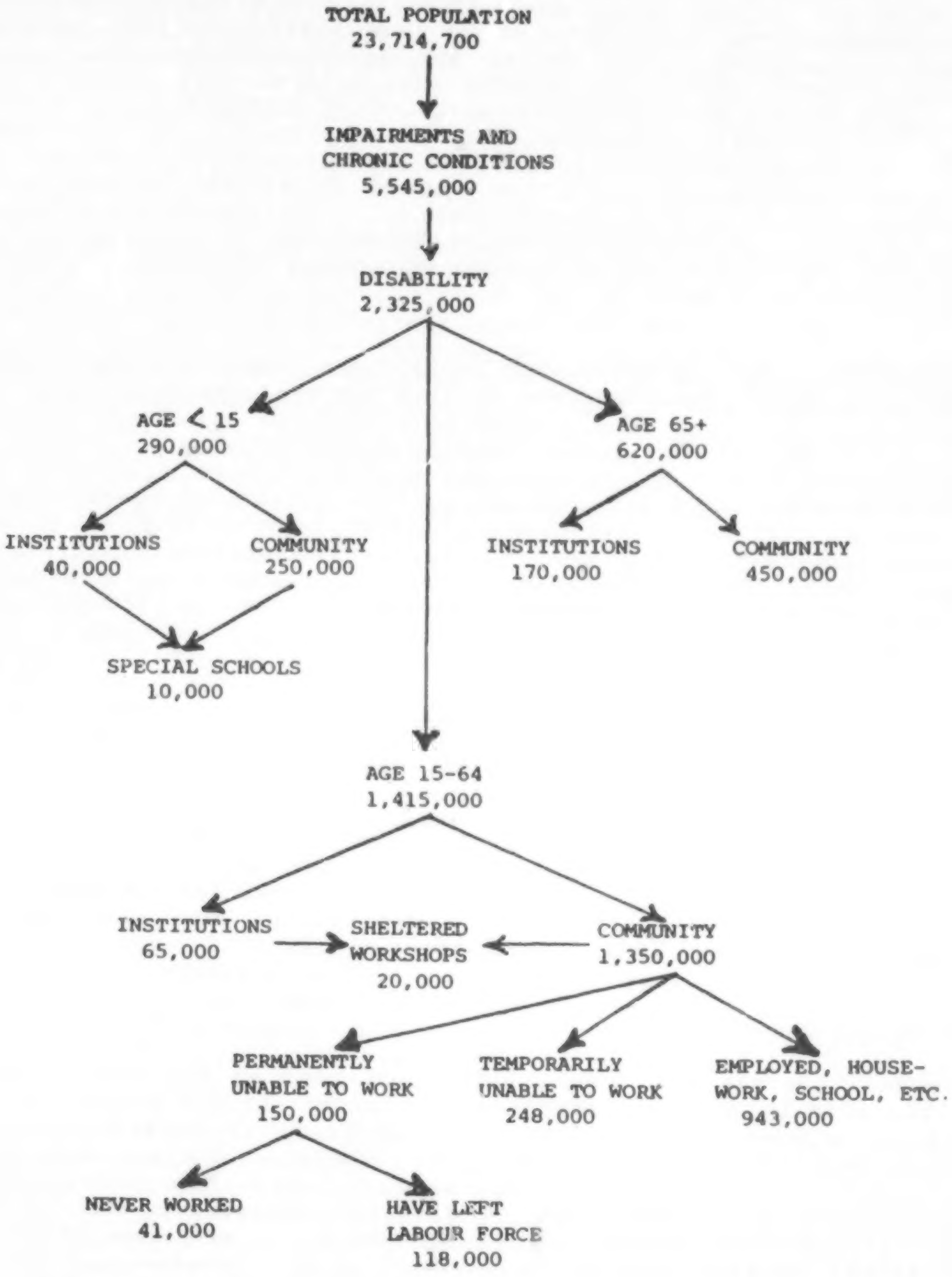
TOTAL POPULATION
23,714,700
IMPAIRMENTS AND
CHRONIC CONDITIONS
5,545,000
DISABILITY
2,325,000
AGE < 15
290,000
AGE 65+
620,000
INSTITUTIONS
40,000
COMMUNITY
250,000
INSTITUTIONS
170,000
COMMUNITY
450,000
SPECIAL SCHOOLS
10,000
AGE 15-64
1,415,000
INSTITUTIONS
65,000
SHELTERED
WORKSHOPS
20,000
COMMUNITY
1,350,000
PERMANENTLY
UNABLE TO WORK
150,000
TEMPORARILY
UNABLE TO WORK
248,000
EMPLOYED, HOUSE-
WORK, SCHOOL, ETC.
943,000
NEVER WORKED
41,000
HAVE LEFT
LABOUR FORCE
118,000

Figure 2. Distribution of disability in Canada in 1979 (from Walker and McWhinnie, 1980)

Walker and McWhinnies's (1980) compilation from a wide variety of data sources seems to be the most reliable guide to the distribution of disability in Canada. After defining disability as "the effects of conditions or impairments on an individual's ability to perform normal daily activities", Walker and McWhinnie estimated that 9.8% of the Canadian population in 1979 was disabled. A breakdown of the 2,325,000 people classified as disabled is given in Figure 2. Of the total disabled population, 275,000 were in institutions: 40,000 children, 65,000 adults, and 170,000 elderly persons. Overall 11.8% of Canada's disabled population, and 1.2% of the country's total population, were estimated to have been in institutions in 1979. These figures, although only approximate, suggest that the potential scope of deinstitutionalization, both preventive and literal, is large indeed in Canada.

SUBSTANTIVE AND METHODOLOGICAL IMPLICATIONS OF THE RESEARCH LITERATURE ON THE EFFECTIVENESS OF DEINSTITUTIONALIZATION

Because of the vast relevant literature and severe time constraints, I relied whenever possible on recent review articles. Empirical studies of the outcomes of deinstitutionalization seem to be most plentiful and rigorous in mental health, less so in mental retardation, and least so in physical disability. I therefore review the literature in the three fields in this order, focusing on substantive and methodological implications for the CCSD study and keeping details to a minimum.

DEINSTITUTIONALIZATION IN MENTAL HEALTH

Five reviews (often overlapping) of the mental health deinstitutionalization literature are summarized here, in reverse order of their year of publication: Barnes and Toews (1983), Kiesler (1982), Straw (1982), Braun et al. (1981), and Test and Stein (1978). Of the five, only Barnes and Toews (1983) is Canadian, the rest are American. (For further information on Canadian deinstitutionalization, a description non-review paper by Richman and Harris (1983) should be consulted.)

Barnes and Towes (1983)

Purpose: Barnes and Toews (1983) provided an overview of studies of the effects of deinstitutionalization on chronic mental patients, with an emphasis on Canadian research but with coverage of other, mainly American, studies. Among the Canadian studies reviewed, two were simple follow-ups (uncontrolled release), two were randomized examinations of alternatives to hospital admission, and one was a quasi-experimental comparison of discharge to the community versus continued hospitalization. No controlled Canadian studies of discharge to different types of community services were discovered, despite the fact that "this type of research is extremely important for determining the conditions which allow patients to remain outside of hospital" (Barnes & Toews, 1983, p. 24).

Substantive Conclusions: Barnes and Toews offered the following tentative conclusions. The follow-up studies, whether controlled or uncontrolled, show that some chronic mental patients are able to adjust to community life and remain outside the hospital for extended periods. Patients served in the community are no worse and possibly better than those served in hospitals, in terms of symptoms and overall adjustment. Patients served in the community appear to be more satisfied with their treatment and life conditions than those in the hospital. Community treatment does not appear to produce greater burdens on families than does traditional hospital treatment, when families are given adequate support. The cost of community treatment is lower than hospital treatment, although whether this advantage can be maintained when community services are implemented on a large scale remains to be demonstrated. Chronic patients, and those with serious disorders not yet classified as chronic, frequently do not perform well in their work and other social roles, and often need sheltered working and living settings. Drugs appear to be important in helping patients remain in the community, an issue virtually unaddressed in Canadian studies to date. Finally, the advantages of treatment in the community disappear once the treatment is withdrawn.

Methodological Conclusions: There are few well controlled studies of the effects of deinstitutionalization on persons with chronic mental conditions, and only one such study has been carried out in Canada, with more needed. The single greatest weakness of the experimental deinstitutionalization research, in the U.S. and Canada, is the lack of demonstrable external validity. That is, will the promising results achieved in the various clinical trials continue when community services are implemented on a broader scale? Finally, in Canada and in other counties, more information is needed on the types of patients and discharge conditions which make for successful deinstitutionalization.

Kiesler (1982)

Purpose: Kiesler's (1982) review addressed three questions: (a) What is the scientific evidence regarding the effects of mental hospitalization? (b) What scientific evidence is available concerning the effectiveness and costs of service alternatives to hospitalization? (c) Are there aspects of hospitalization that might have negative effects on the individual?

To answer these questions, Kiesler located many experimental (rather than quasi-experimental or purely correlational) studies of the effects of institutionalization compared to alternative types of services. He was able to locate 10 studies, nine "true experiments" (with random assignment to a hospital and alternative setting) and one "near experiment" (with assignment of all clients during an initial 5-month period to an in-patient unit, followed by assignment of all clients during a second 5-month period to a non-hospital program).

Substantive Conclusions: According to Kiesler, the findings directly contradict the **de facto** U.S. policy of hospitalization psychiatrically impaired people. Kiesler notes that despite a **de jure** U.S. policy of deinstitutionalization, there are currently 1,800,000 admissions to mental hospitals each year, the rate of hospitalization per 100,000 population was greater in 1975 than in 1955, and 70% of mental health funds are spent on hospitals.

The results of the 10 studies indicated that the alternative services were never worse than hospitalization (in the 10 studies the hospital was probably better than many institutions) and, in fact, in almost every study, alternative services had more positive outcomes. The more favorable effects of the alternative services were observed on a wide array of measures, including psychiatric evaluations, subsequent employment, school performance, maintenance of long-term relationships, and independent living arrangements. In no case did the cost of the alternative services exceed that of hospitalization. The rate of repeat hospitalization for persons treated in hospital was higher (in some studies, much higher), suggesting that hospitalization becomes self-perpetuating. Finally, it appears very plainly that too many people are now being hospitalized (although Kiesler adds that the 10 studies do not address the question of whether it is necessary to institutionalize anyone at all).

Methodological Conclusions: Kiesler points out that policy concerns in the face of current, empirically unsupported fiscal expenditures of billions on hospitalization and virtually nothing on "preventive non-institutionalization" demand that we begin to find out what is effective in mental health. The 10 studies strongly support the usefulness of true, randomized experiments for determining effects, and make Kiesler's (1982) paper one of the most valuable review articles in the literature on deinstitutionalization.

Straw (1982)

Straw's (1982) doctoral dissertation, a meta-analysis of the mental health deinstitutionalization literature, is certainly the most comprehensive review available. His analytic technique, meta-analysis, consists of a set of procedures for conducting a quantitative (rather than traditional qualitative) review. His search of the literature appears to have been more extensive than in the case of the other reviews, and yielded 85 studies included in the meta-analysis. These 85 studies each compared some "innovative" treatment with a "traditional" mental health treatment, and were distributed among three broad categories: (a) the effects of brief hospitalization compared to routine in-patient care (9 studies); (b) the effects of community-based services compared to standard hospital care (30 studies); and (c) the effects of special outpatient programs compared to traditional aftercare services (49 studies). (Note: Straw (p.74) states that 85 studies were finally included in his meta-analysis but does not explain why 86 are on his appended list of included studies (pp. 201-208), nor does he comment on the apparent discrepancy between the number 85 and the 88 studies cited).

Substantive Conclusions: Straw (1982) listed the following substantive findings as "highlights" of his complex analyses: brief hospitalization produces the same outcomes as longer stays, and is obviously less expensive. The evaluations of alternatives to hospitalization "demonstrate quite convincingly that most, if not all, patients who might be hospitalized can be treated in the community" (p. 154); however, the evidence available does not permit a clearcut conclusion that the innovative treatments are superior on any outcome, nor can we infer that the lower costs of the new models would be maintained if they were implemented nationally. When drugs are taken as prescribed, they are a very effective "aftercare" (post-hospitalization) treatment. The evaluations of alternatives to traditional aftercare services indicate that some innovations are more effective than others, although none seem much effective than medication plus well-administered support. Across all studies, innovations explicitly designed to rehabilitate produced more impressive vocatianal achievements. Innovative treatments that were relatively strong and of long duration (compared to traditional treatments) were also more effective.

Overall, Straw (1982) concluded that the results of his meta-analysis suggest several treatment components which could increase the effectiveness of existing programs:

> a) Insure that those who need medication take it in adequate doses.
>
> b) For the seriously ill, provide highly structured skills building treatments ("rehabilitation") for as long as it takes to meet the individual needs of the patient.
>
> c) Provide extended, or at least readily available, support for most patients - and make it readily accessible.
>
> d) If there is no alternative, at least reduce the length of an in-patient episode to the shortest duration possible, consistent with the needs of the patient. (Straw, 1982, p. 168)

Methodological Conclusions: Several of Straw's major methodological findings and suggestions are worth noting. Interestingly, he found that studies which were high in internal validity (employed random assignment) did not produce a larger or smaller outcomes than studies which used non-randomized, quasi-experimental designs. Hence, in meta-analyses, we should not exclude, on a

priori grounds, studies that do not fulfill the conditions of a true experiment. On the other hand, in the design of any **new** evaluation study, "random assignment and blind assessment remain the best choices for obtaining unbiased estimates of treatment effects" (p. 156). Three methodological factors were found that suggest caution in interpreting the policy suggestions of the meta-analysis: the stronger the authors' rated "allegiance" to the innovative treatment, the more ambiguous the blinding of assessments; and the higher the rated reactivity of the measures, the greater was the "effect size" (magnitude) of the outcome found. Hence, studies with adequate measurement designs (in addition to random assignment) are needed, with blind assessment for all outcomes (including hospital readmissions) and totally independent evaluation teams. New and better studies of the cost of alternative mental health programs, and research on the organizational factors which promote institutionalization are required. Finally, a number of groups -- publishers of computerized databases, journal editors, funders of major evaluations, etc. -- must take steps to make meta-analyses easier to conduct and to recognize meta-analyses as a research technique "which deserves to be treated on an equal basis with primary research studies" (Straw, 1982, p. 175).

Before going on to the next review, I should underline the relevance of Straw's last observation for the CCSD study. Meta-analyses of the deinstitutionalization literatures in mental retardation and physical disability seem well worth considering, before any new field evaluations are attempted. Straw's dissertation could serve as a model.

Braun et al. (1981)

Purpose: Braun et al. (1981) had the primary aim of examining critically how deinstitutionalization affects psychiatric patients. They confined their review to "controlled trials" (which, however, included non-randomized quasi-experimental studies as well as true, randomized experiments) and grouped these trials into three categories: (a) studies of alternatives to hospital admission, such as community services (7 studies, 5 randomized), (b) studies of modifications of traditional hospitalization, such as shorter hospital stays, or use of "day care" (8 studies, 6 randomized); and (c) studies of alternatives to continued long-term hospitalization, such as non-hospital care for "chronically ill" psychiatric patients who had been hospitalized for extended periods of time (5 studies, 4 randomized). The 20 studies comprised, according to Braun et al., "all the controlled experimental trails we were able to find as of mid-1979 on alternatives to conventional psychiatric hospitalization" (p. 747).

Substantive Conclusions: Despite dismay at finding so few scientifically rigorots studies of deinstitutionalization, Braun et al. concluded that the limited evidence supports the following conclusions: it is feasible to "manage" previously hospitalized psychiatric patients in experimental community programs; selected patients admitted to alternative programs, as well as those in modifications of conventional hospitalization, have psychiatric outcomes as good as, and sometimes superior to, those of hospitalized control patients; and deinstitutionalization is not likely to be successful in the absence of continuing services in the community. The conclusions of Braun et al. (1981) are similar to those of the previous reviews.

Methodological Conclusions: Braun et al. mention several desiderate, in any deinstitutionalization research, to overcome the weaknesses in their 20 studies: random allocation to experimental and control programs; careful description of background characteristics of study participants and use of well-validated clinical assessment instruments; detailed description of the experimental and control programs; outcome assessment (of psychosocial status, clinical status, quality of life, and functional status) with psychometrically adequate tools; follow-up over a sufficiently long period of time; and large enough samples for appropriate statistical analyses.

Test and Stein (1978)

Despite the fact that it is now somewhat dated, Test and Stein's (1978) review article is still worth close attention because of its clinical and methodological incisiveness.

Purpose: The architects of one of the most effective and influential community-based programs for persons with chronic psychiatric impairments (cf. Stein & Test, 1978, 1980; Test & Stein, 1980), which also generated the most adequate cost-benefit analysis in the entire deinstitutionalization literature (cf. Weisbrod & Helming, 1980, and Weisbrod, Test, & Stein, 1980), Test and Stein (1978) reviewed prospective experiments of "community treatment" for "chronic patients", the majority of whom were labelled "schizophrenic". Test and Stein were primarily interested in the direct implications of the well-controlled studies for program development and clinical practice.

Substantive Conclusions: According to Test and Stein, the 28 randomized or quasi-randomized experiments they reviewed permit the following generalizations: community programs make it possible to avoid almost completely the hospitalization of persons with non-organic chronic impairments; these positive results are maintained, however, only as long as the community programs are in effect, meaning that continuing rather than time-limited services are needed; of even more practical significance is the evidence that such services may be a **necessity** to prevent the readmission of people who have previously been hospitalized -- without community services, recidivism is extremely high, but is greatly reduced when they are available; there is "overwhelming" evidence that the adjustment and quality of functioning of patients served in (rather than "dumped" into) the community are no worse than those treated in the hospital; consumer satisfaction is higher in clients treated in the community than in those in hospital programs; and at least modest gains in psychosocial functioning in the community can be achieved through direct and intensive intervention in daily living in the community, and such gains are maintained as long as intervention lasts.

Methodological Conclusions: Test and Stein made several recommendations for improved research on community treatment. Homogeneous populations should be used, with careful specification of at least the following characteristics: diagnosis (using research criteria), age, sex, education, socio-economic status, a measure of chronicity, and age at onset of the condition. A sensitive instrument to measure community adjustment needs to be developed, especially for difficult-to-measure areas of community adjustment such as daily living kills, social activity, social relationships, quality of life, and satisfaction with life. Finally, research should put a priority on intervention involving both the impaired person and his or her family, the relationship between stress and adaptation, medication and compliance issues, the burden possibly placed on families by community programs, and the economic implications of different treatments. (These methodological pointers obviously have as much relevance for deinstitutionalization programs serving developmentally and physically impaired persons as they do for services to those with psychiatric impairments.)

DEINSTITUTIONALIZATION IN MENTAL RETARDATION

Research on deinstitutionalization in mental retardation appears to be soemwhat less abundant and less rigorous than research in mental health. According to Heal and Fujiura, there are only four "true" (randomized) experiments in which institutionalized residents were assigned to community placement versus continued institutionalization. Moreover, two of the four studies are really "analogue" deinstitutionalization studies, in that they investigated residents who moved from an institution to cottages or duplexes located on the institution's grounds. An additional randomized experimental deinstitutionalization, recently funded in Canada (Laurendeau, Blanchet, & Coshan, 1983), involves the transition from a large institution to group homes located in the community in Montreal.

In the mental retardation literature, the key reviewer and synthesizer of the deinstitutionalization research is Laird Heal (Heal, Sigelman, & Switzky, 1978; Novak and Heal, 1980), and I limit attention to the work of Heal and his colleagues. In passing, however, I wish to call attention to the new, previously cited chapter by Heal and Fujiura, because of its relevance to the methodological concerns of this paper. Heal and Fujiura survey the numerous methodological pitfalls encountered in research on the training and placement of developmentally disabled persons in public and community settings, and illustrate their superb discussion with many examples from the very recent literature. For those who may be tempted to settle for less then rigourous standards of applied research on deinstitutionalization, quolation from their chapter "The Ethics of Applied Science" may serve as a needed, sobering caution:

> From the above it is clear that social scientists have developed an elaborate system of methodological conventions, and the validity of research on residential alternatives for developmentally disabled individuals depends upon its adherence to these conventions. But research on residential alternatives has fallen short in all regards. Ecological Validity has usually been ignored... Measurement Validity is nearly always assumed by the author... Internal Validity has been flawed by the unfortunate custom of using intact, rather than randomized, groups. The applied scientist must challenge the assertion of practitioners that "best practice" is incompatible with this essential prerequisite of Internal Validity. The number of studies... that have accomplished random assignment has been embarrassingly few... Finally, Social Validity is seldom assessed... We are remiss as scientists to tolerate the present state of affairs. We charge ourselves with the responsibility of providing society with information that it needs to make decisions about the provision of residential services for its developmentally disabled citizens. With this responsibility comes the obligation to advocate for the best methodology that we know. We have clearly failed to meet this obligation. (Heal & Fujiura, in press.)

The implications for the CCSD study are clear: high but not unattainable standards, and nothing less, will do. We now return to the conclusions contained in the earlier reviews by Heal and his colleagues.

Substantive conclusions. Several overriding generalizations emerge from Heal et al. (1978). Characteristics of the deinstitutionalized mentally retarded person are not very good predictors of community adjustment; on the other hand, problem behaviour is the most predictive of placement failure. Compared to individual factors, community and program environmental factors appear to be relatively good predictors of community adjustment; overall, successful deinstitutionalization appears to depend more on the quality of community support than it does on individual client characteristics. Enhanced placement success may lie in better understanding and manipulation of client interaction with the setting, so that individuals are "matched" to settings optimal for them. Despite the poor quality of much of the research, some recent data support the assertion that there are cost-efficient, community-based, "normal" alternatives to large, segregated residential facilities.

Methodological conclusions. Heal et al. (1978) stress several themes that would greatly improve the quality of deinstitutionalization research in mental retardation (as well as in mental health and physical impairment). The most serious shortcoming is the continuing lack of randomized experimental studies with control groups (it is sobering to realize that McCarver and Craig (1974) were unable to establish **any** firm conclusions from their review of 175 correlational studies of community adjustment). Random assignment of deinstitutionalized residents to all viable community residential options is necessary in the absence of compelling administrative, ideological, or personal reasons against randomization. If randomization is not feasible, the strongest possible quasi-experiments and statistical controls are essential, especially in examining interaction with the environment. Future studies of deinstitutionalization and community adjustment must become increasingly longitudinal in nature.

All of these suggestions are pertinent for the CCSD study. The emphasis placed by Heal et al. (1978) on measurement of the environment also ties in with a later section on PASS 3 as one possible method of environmental assessment (see also Heal & Laidlaw, 1980).

DEINSTITUTIONALIZATION IN PHYSICAL IMPAIRMENT

Unlike mental health and mental retardation, physical impairment as a service field, has never had a massive and far-flung empire of residential institutions, with the partial exception of schools for the visually and hearing impaired. As a result, physical impairment has not developed a well-defined tradition of deinstitutionalization research. (Unfortunately, if placement of physically impaired people in chronic care institutions and nursing homes continues to increase in the future, then the field may very well have to create deinstitutionalization literature in a few years.)

In the absence of a body of studies or appropriate review article to summarize, I shall restrict attention here to the work of the most active empirical researcher at present in the independent living (IL) tradition, Gerben DeJong. DeJong (1979) considers IL to be both a social movement and a new paradigm for disability-related research, with a strong orientation towards civil rights, consumerism, self-help, demedicalization and increased self-care, rejection of much of the traditional medical model and sick or impaired role, and finally, an enthusiasm for the sister ideologies of deinstitutionalization, "mainstreaming", and normalization.

Two of DeJong's recent articles are important contributions to the IL literature, both substantively and methodologically. First of all, DeJong, Branch, and Corcoan (1984) specified and then tested an IL-derived model of successful community outcomes among persons with spinal cord injury. The model included personal and medical variables but had a much stronger environmental component than does most disability-related research. In a multivariate predictive test of the models with a sample of 75 young persons with spinal cord injury, DeJong et al. (1984) found that living arrangements, productivity, and overall independent living outcomes (a composite of the two preceding variables) were highly related to a small set of predictors (multiple R's varied from .79 to .82). Consistent with the IL model, environmental variables such as transportation barriers, economic disincentives and marital status were important predictors of outcomes, along with several personal predictors, including education and severity of disability.

From a methodological point of view, DeJong and Hughes' earlier (1982) paper on how to measure long-term IL outcomes is also noteworthy. The method outlined there consisted of an examination of outcomes for 111 spinal cord injured persons discharged from 10 medical rehabilitation centres in the U.S. The outcomes were ranked and weighted by an interagency panel made up of service providers, consumers, and funding agencies. Statistical analysis indicated a high level of agreement among judges about how each outcome should be ranked and weighted. DeJong and Hughes (1982) concluded that the methodology is workable and able to take account of the value judgements inherent in developing long-term outcome measures for the effects of IL and medical rehabilitation programs.

PASS 3 AS A METHOD FOR ASSESSING SERVICE QUALILTY IN COMMUNITY AND INSTITUTIONAL PROGRAMS

PASS 3 AS A PROGRAM EVALUATION TOOL

PASS 3 (Wolfensberger & Glenn, 1975a, 1975b) is used by an external team of trained raters to assess a service program on 50 different ratings, (34 items relating directly to normalization, 16 to administrative issues, broadly defined; cf. Wolfensberger, 1975b). After a site visit of one to three days, individual team members first rate the service independently and later resolve any differences in their ratings in a team-reconciliation session. The reconciled ratings on each of the 50 PASS items are then converted to weighted scores (cf. Wolfensberger & Glenn, 1975a). A score of zero on any rating or on the total PASS score (the sum of all 50 ratings) signifies "minimally acceptable" service quality. The total PASS score, an index of overall service quality, can range from + 1,000 ("ideal" quality) to -947 ("abysmal" quality).

PREVIOUS PASS RESEARCH

In an earlier review of PASS-based research (Flynn, 1980, p. 331), I drew several conclusions that still seem valid:

1. Overall service quality, as indexed by the total PASS score, appears to be only modest in the "average" human service program. Moreover, program elements that are

central to the normalization principle, such as social integration, model coherency, and intensity of relevant programming, are often especially weak.

2. PASS appears to have considerable discriminant validity, in that it can differentiate quantitatively between different types of services, whether the differentiation is relatively large (such as institutional versus community programs) or more subtle (such as community child development versus community residential). Community services consistently receive higher PASS scores than institutional programs and, among rommunity services, child development programs outscore other types.

3. PASS measures service dimensions which constitute culturally valued processes and outcomes in and of themselves, such as social integration, developmental growth, strvice proximity and accessibility. These dimensions also, in some cases, appear to be associated with client developmental gains.

A NEW PASS 3 STUDY

PASS 3 (hereafter simply "PASS") may be useful for the CCSD study of deinstitutionalization because, unlike many evaluation tools, it was explicitly designed to apply to virtually any type of service (residential, vocational, educational, etc.) and to virtually any type of clientele (developmentally, psychiatrically, or physically impaired). Moreover, the fact that PASS is grounded in the normalization principle makes it very strongly oriented to deinstitutionalization issues such as social integration, maximization of competencies and skills, or, more generally, quality of life. To illustrate the potential value of PASS for the CCSD study, I shall now summarize the findings from a monograph currently in preparation.

Sample

The sample was composed of 519 PASS 3 evaluations carried out in the U.S.A. (69%) and Canada (31%) between 1975 and 1983. The sample was an accidental one, consisting of those evaluations sent to the author by a large number of PASS users in response to requests. All evaluations were in the form of team-reconciled scoresheets. (It should be noted that 256 of the 519 evaluations formed the data for an earlier, similar study, Flynn, 1980).

About two-thirds of the 519 evaluations were conducted during introductory PASS 3 workshops, 5 per cent during advanced workshops, and 15 per cent were from "official" evaluations. Eighty-one per cent were evaluations of community-based programs, and 59 per cent were evaluations of programs serving adults. Fifty-three per cent of the programs were in the field of mental retardation, 10 per cent in mental health, 5 per cent in aging, and 4 per cent in physical and sensory impairment. Eighty-five per cent of the programs were "segregated", meaning they served "deviant" clients only. Forty-two per cent of the programs were community-based residential services, 4 per cent were mini-institutions, 8 per cent were institutional residential programs, 9 per cent were mainly community-based child development services, 6 per cent were mainly community-based educational programs, and 17 per cent were mainly community-based vocational services. Finally, 58 per cent of the programs evaluated were run by private, non-profit agencies, with 26 per cent operated by public agencies.

Construction of PASS Subscales

In order to compare the quality of different types of programs, community-based and institutional, the total (50-item) PASS 3 scale, as well as four derived subscales, were used. To construct the subscales, factor analysis (principal factoring, with varimax rotation) was employed with the full sample of 519 evaluations. The four PASS subscales that emerged were very similar, though not identical, to the four subscales used in Flynn (1980).

Normalization Program. This first subscale was composed of 16 items that all have a focus on the "content" (processes and outcomes) of a program, and may be seen as a measure of the "quality of life" which clients experience in the program. The subscale includes items tapping constructs such as participation in socially integrative social activities, age and culture-appropriate personal appearance, age and culture-appropriate labels and forms of address, age and culture-appropriate autonomy and rights, model coherency, lack of social overprotection, and growth-enhancing developmental experiences (intensity of relevant programming, individualization, and supportive interactions). Normalization Program had an internal consistency (alpha) reliability of .90, and correlated very highly ($r = .93$) with the total PASS score (which itself had alpha reliability of .91).

Normalization Setting. This second PASS subscale was made up of 11 items that measure the quality of the physical facility in which the program is located, and the quality of the surroundings of the facility and program. The subscale taps constructs such as program-neighbourhood harmony and building-neighbourhood harmony, the relationship between the number of clients served and the likelihood of their being absorbed and integrated into the surrounding community social systems ("congregation, and assimilation potential"), the exterior and interior design and decor of the facility, and the building's physical comfort and environmental beauty. Alpha reliability for Normalization Setting was .79, and the subscale correlated highly ($r = .75$) with the total PASS score.

TABLE 1

Pearson Intercorrelations, Means, and Standard Deviations for Total PASS 3 Scale and Four PASS Subscales, in the Sample as a Whole (n = 519)

Scale/Subscale	TPS	NP	NS	A	PA
Total PASS Scale	--				
Normalization--Program (NP)	.93	--			
Normalization--Setting (NS)	.75	.57	--		
Administration (A)	.59	.45	.31	--	
Proximity & Access (PA)	.39	.24	.28	.11*	--
Metric - weighted scores:					
Mean:	-124.97	-113.80	-2.30	-38.88	33.50
SD:	282.74	165.41	63.92	46.27	36.53
Metric - per cent of maximum possible score:					
Mean:	42.22	35.81	51.46	34.90	69.94
SD:	14.52	20.62	18.00	17.53	21.74

* $p < .02$ (two-tailed); all other correlations significant at $p < .001$ (two-tailed).

Administration. This third PASS subscale was formed from eight items dealing with program management and agency self-renewal issues. These items include consumer and public participation, education of the public, ties to academic institutions, staff and manpower development, administrative control and structures, planning process, and program evaluation and renewal mechanisms. Administration had an alpha reliability of .71, and correlated moderately (r - .59) with the total PASS score.

Proximity & Access. This last PASS subscale was made up of four items: the physical proximity of the program to local and regional populations, the speed and convenience with which clients, their families, and the public can get to the service, and the proximity and accessibility of the service to shops, libraries, post offices, banks, restaurants, etc. Proximity & Access had an alpha reliability of .67, and correlated modestly (r - .39) with the total PASS score.

Major Findings

Service quality in the sample as a whole: As is shown in Table 1, along with the correlations among the total PASS scale and four subscales, the mean total PASS score for the sample of 519 program evaluations was -124.97 (in the usual PASS metric of weighted scores). As a percentage of the maximum possible score (-947 to + 1,000 - 1,947 points), the mean of -124.97 was equal to an overall total PASS score of 42 per cent, well below the 50 per cent mark that, for Wolfensberger and Glenn (1975a), represents "minimally acceptable" service quality.

On the four PASS subscales, the mean performance of the sample as a whole was only well above the minimally acceptable level on Proximity & Access (70 per cent; see Table 1). Service quality was "minimally acceptable" on Normalization Setting (51 per cent), but considerably less than minimally acceptable on the most important subscale, Normalization Program (36 per cent), as well as on Administration (35 per cent).

Service quality in different types of programs. There were five types of programs in the sample in sufficient numbers to permit meaningful between-program comparisons: community-based child development programs (n - 45), community residential programs (n - 205), community educational programs (n - 31), community vocational programs (n - 79), and institutional residential programs (n - 38). Figure 3 compares the mean total PASS scores of these five types of services expressed in the "per cent of maximum possible score" metric. Only the community child development programs surpassed the 50 per cent mark of "minimally acceptable" service quality. In terms of comparative quality, all four types of community programs scored higher ($p < .01$) than the institutional residences, with the child development services also superior to the other three types of community programs ($p < .01$). The only other statistically significant difference lay in the higher score of the community residences than the community vocational services ($p < .05$).

Figure 3

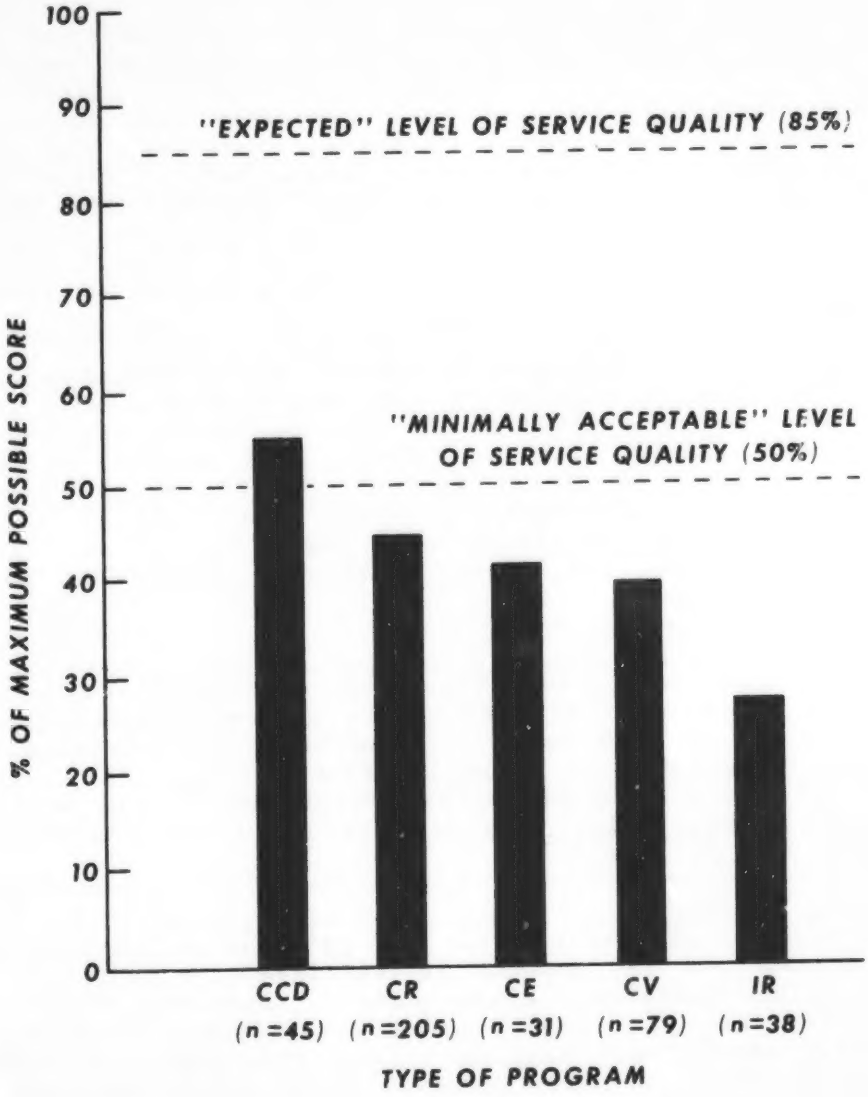

Figure 3. Mean total PASS score by type of program (CCD - community child development; CR - community residential; CE - community educational; CV - community vocational; IR - institutional residential).

Figure 4 carries the between-programs comparative analysis a step further by presenting mean scores of the five types of services on the four PASS subscales (the metric is again per cent of maximum possible score). A preliminary multivariate analysis of variance showed the presence of a significant programs-by-subscales interaction in the data (multivariate $F(12, 1179) = 11.72$, $p < .001$); that is, the PASS profiles in Figure 4 were not parallel. Between-program comparisons thus had to be made (by univariate analyses of variance) on each of the four subscales, one by one. Similarly, the significant interaction also meant that between-subscale comparisons had to be made within each of the five groups of programs separately. In each of these analyses (4 between-groups and 5 within-groups), the F-ratio was significant ($p < .001$), and **post hoc** pairwise comparisons among means were then carried out.

Figure 4

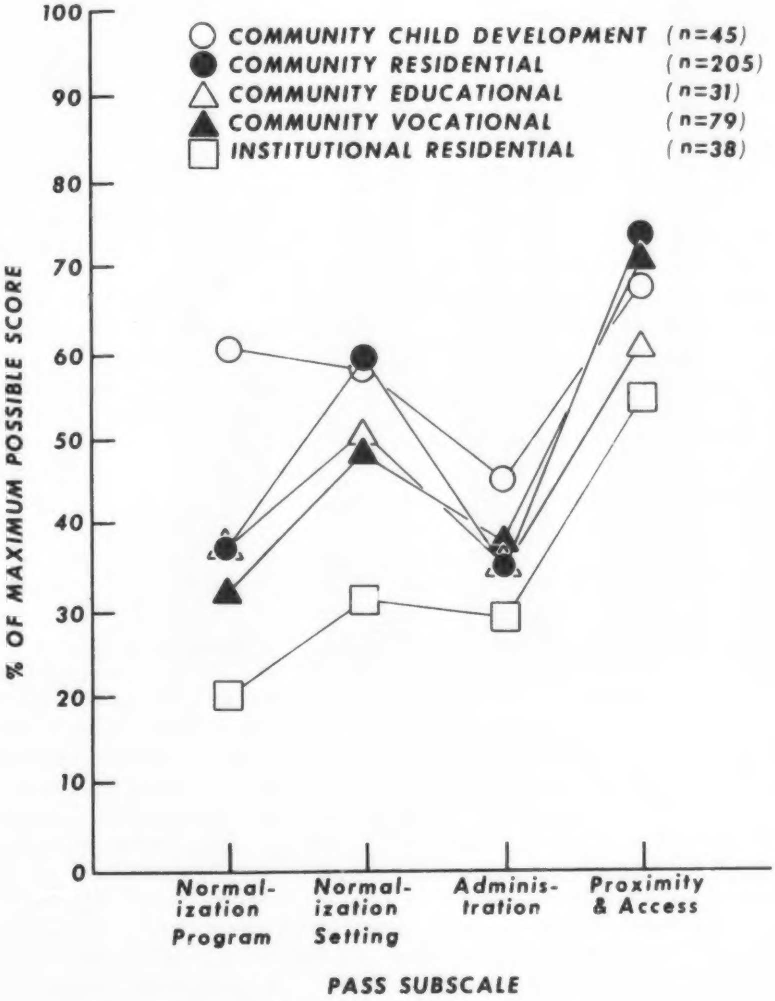

Figure 4. Mean score on PASS subscales by type of program.

The findings may be summarized as follows: On Normalization-Program, the four types of community programs scored higher than the institutional residences ($p < .01$), and the child development services were of higher quality than the other groups of community programs ($p < .01$). On Normalization Setting, all four groups of community services were again superior to the institutional residences ($p < .01$), and the community residences were of higher quality than the community educational ($p < .05$) and vocational programs ($p < .01$). The child development programs also scored higher than the communtiy vocational services ($p < .05$). On Administration, there were only two statistically significant differences: the community child development programs scored higher than either the community residences ($p < .01$) or the institutional residences ($p < .01$). Finally, on Proximity & Access, there were likewise only two significant differences: the community residences and the community vocational programs both scored higher than the institutional residences ($p < .01$).

The comparisons between subscales, evident in Figure 4, are easier to visualize in the form given in Figure 5. Within the community child development programs, the only significant difference lay in the fact that the mean for Administration was lower ($p < .001$) than the means of the other three PASS subscales. In the community residences, all pairwise differences were significant ($p < .001$) except for the one between Normalization Program and Administration. In the community educational programs, all of the means were different ($p < .002$ or less) except those for Proximity & Access versus Normalization Setting and Normalization Program versus Administration. Within the community vocational programs, five of the six pairwise differences were significant at the $p < .001$ level, and the sixth was significant at the $p < .008$ level. Finally, in the institutional residences, all of the pairwise mean differences were significant ($p < .001$) except two: Normalization Setting versus Administration and Administration versus Normalization Program.

Conclusions Regarding PASS 3

The previous analysis suggests that PASS 3 may be a suitable method for consideration in CCSD's study of the cost-effectiveness of deinstitutionalization. Both the total scale and derived subscales show internal consistency that ranges from good to adequate and a high degree of discriminant validity. Substantively, this PASS 3 study, like previous PASS research, suggests that community services are of consistently higher quality than institutional services, even though there is much room for improvement in the community programs.

Figure 5

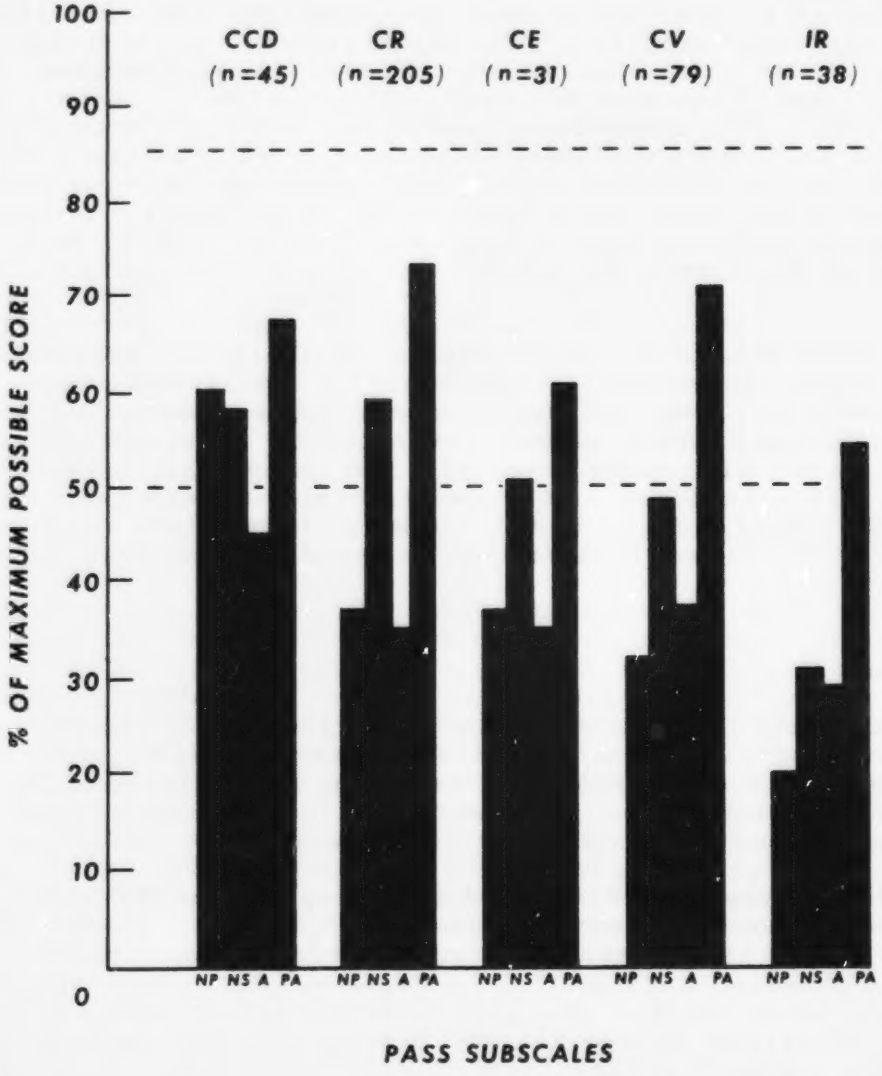

Figure 5. Mean score on PASS subscales within different types of programs. Upper broken line, at 85% level, is "expected" level of service quality; lower broken line, at 50% level, is "minimally acceptable" level. (CCD - community child development; CR - community residential; CE - community educational; CV - community vocational; IR - institutional residential).

If PASS 3 were to be used in the CCSD study, it would, of course, be preferable to use the full 50-item scale (which would simultaneously permit use of the four derived subscales). However, should resources make this impossible, an alternative course would be to use only the 16-item Normalization Program subscale, which correlates .93 with the full-length scale. Another option would be to use the 18-item, 3-subscale PASS 3 short form described in Flynn and Heal (1981). Although derived especially for assessing community residential programs, the short form has a high multiple correlation with the total PASS (50-item) score within community and institutional programs, community child development, community day treatient and counselling services, and community educational and vocational programs. High interrater reliability coefficients are attainable on both the total PASS scale and the PASS short form, even with small rater teams (Flynn & Heal, 1981). Regardless of the version, if PASS were to be used, rater should need thorough training and field experience with the complete 50-item tool.

As a final comment, Wolfensberger and Thomas (1983) have recently published PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals). PASSING measures service quality only in terms of the service's implementation of normalization, unlike PASS which assesses quality in terms of the service's implementation of normalization, certain other service values ("ideologies"), and several administrative desiderata (Wolfensberger & Thomas, 1983, p.3). Given the recent appearance of PASSING, there is no research on it yet, to the best of my knowledge.

Conclusion

This paper responded to Dr. Harry MacKay's question, "Would you be able to present a paper on the methodologies used and technical problems encountered in determining effectiveness in relation to deinstitutionalization programs?" In conclusion, I wish to offer several broad suggestions for the CCSD study.

First, the study needs a conceptual unity that may be threatened because it extends to several client groups with very different impairments, disabilities, or handicaps. The World Health Organization model (1980) is, I believe, one means of conferring conceptual unity on the overall research effort and is compatible with the diversity of operational definitions and measures. Within the outcome categories specified in the WHO model, I would concentrate most on handicaps, next on disabilities, and least on impairments. For the alleviation of handicaps and the promotion of optimal performance in key social roles (orientation, physical independence, mobility, occupation, social integration, and economic self-sufficiency, in the WHO schema) are the ultimate goals of deinstitutionalization and rehabilitation.

Substantively, the study should be careful not to "bite off more than it can chew". Ideally, I would prefer to see something like the following:

a. Over the next year or two, a technically sophisticated review and synthesis of the deinstitutionalization literature on costs and effects should be carried out, with an eye both to scientific validity **and** policy utility (the former is a condition of the latter). The methods of meta-analysis, used by Straw (1982) for mental health, could be extended successfully to mental retardation and physical impairment. Some other less rigorous, more qualitative method might be used for research integration. Once completed, this initial "product" should be widely disseminated, in several different formats, to policy-makers, federal and provincial civil servants, voluntary associations, practitioners, and researchers in Canada.

b) Concurrently, it would be useful -- as some suggested at the Symposium -- to describe in a non-rigorous, informal way some of the more promising methods of community integration current in Canada and elsewhere. This portrait should also include some "horror stories" on what appears not to work. This second product, distinct from the research synthesis in (a), should be widely distributed to the same audiences.

c) Upon completion of the CCSD study, likely to prove a preliminary one, ambitious, long-term studies on deinstitutionalization and community integration should be started in Canada, with joint federal and provincial participation and funding. Such a long-term effort would need high research standards, if the disappointing yield of past efforts (as well as the sheer lack of Canadian research) is to be overcome. Without such long-term follow-up, I doubt that the CCSD research can accomplish very much by itself. On the other hand, if it provides the impetus for a strong tradition of well-designed and funded Canadian deinstitutionalization studies, then the CCSD study will indeed be a landmark.

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THE REMAINING TASK OF DEINSTITUTIONALIZATION: OBSERVATIONS FROM A NEEDS ASSESSMENT STUDY OF THE SEVERELY PHYSICALLY DISABLED IN ONE COMMUNITY

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The Ottawa-Carleton Regional District Health Council (1984), in conjunction with the Royal Ottawa Regional Rehabilitation Centre, has recently completed a needs assessment study of the accommodation and support care of the severely physically disabled aged 0-64 in Ottawa-Carleton. This paper reports some of the findings from the study and draws some implications for a study of the costs and effects of deinstitutionalization. The needs assessment study is representative of several that have recently been completed or are underway in Ontario (1). The appearance of these studies indicates that the recommendations of the Obstacles report are beginning to filter down to the local planning level.

The theme of the paper is where our community stands now on deinstitutionalization, how far we have to go, and how economic analysis could assist in making choices among alternatives. The question in the first part is: "Among the physically disabled under 65, who is currently left in institutions?" In the second part, we turn to make some tentative suggestions for areas of concentration for a national study of costs and effects of deinstitutionalization. To put the matter in perspective, we shall also look briefly at some data on the developmentally disabled, psychiatric and disabled elderly populations in the same community, drawing on other sources. In our opinion the major issue is no longer to answer the generic question, "Is deinstitutionalization cost-effective?" because we think that this has largely been answered, but to come up with concrete planning guidelines for the optimal volume and type of community residential accommodation and services, and to examine how economic analysis can help us decide what to tackle first in the task of deinstitutionalization.

As a springboard to jump into big issues like this, our study has some obvious limitations. The needs assessment consisted of a number of surveys: a survey of children and adolescents 0-18 in institutions outside Ottawa-Carleton; a survey of chronically ill children occupying acute care beds inside Ottawa-Carleton; a survey of severely disabled children living in the community; a survey of adult multiply handicapped persons living at Rideau Regional Centre, the large provincial facility for the developmentally disabled, in Smith's Falls outside Ottawa; a survey of physically disabled adults housed in health facilities inside Ottawa-Carleton; and a survey of severely physically disabled adults living in the community (2). Although the institutional surveys were fairly complete, the community surveys suffered some inevitable sampling problems. The focus of the surveys was on socio-demographic and functional information as well as perceived present and future housing and support care needs.

The target group was limited to the severely disabled, defined in terms of the need for assistance from others with one or more of the basic personal care activities of eating, dressing, bathing, grooming, transfess and elimination. Our study was unable to look in depth at the issue of quality of life, or ancillary needs such as vocational, educational and recreational services. Nor did it look at costs. We more or less assumed that community alternatives were equally as effective or more effective than institutions.

Before going into the results of the surveys, a word about the evolution of the system in Ottawa-Carleton. Big changes have taken place in the last decade. Up until the mid-seventies the choice for a severely disabled person was limited to going home or going to an institution. Then, beginning in 1975, a gradual expansion of community residential alternatives occurred. Group homes such as CORDI House, TELCI and Parkway House began, and the Rehabilitation Institute opened its accessible apartments with 24 hour on-site support care. By the time of the study, there were 72 community residential places with support care for the physically disabled, 39 in support apartments, 33 in group homes. Other expansions were being planned. For those living at home who could establish a need for professional services, the advent of chronic home care brought access to much-needed homemaker services. The creation of a transportation system, and increasing efforts to remove barriers, have made the environment more accessible.

The options in the community for severely disabled children, however, remains extremely limited. Since 1974, Ottawa has had no chronic institutional facility for children and only one group home (restricted to those with sensory impairments), so severely disabled children requiring out-of-home placement still must be placed outside Ottawa-Carleton unless they are assigned to the custody of the Childrens' Aid Society and are placed in foster homes.

Well, after 10 years, where is this community now in terms of residual needs? We shall deal with the results from the major surveys in turn.

First, the composition of the institutionalized population outside Ottawa-Carleton is of interest. Sixty-six children and adolescents from Ottawa-Carleton were in facilities across southern Ontario, but mainly within 80 miles of Ottawa-Carleton. Of these, data were obtained from officials of the facilities for 54. Most are in their teenage years, indicating the tendency in recent years to avoid institutional placement. Most are developmentally disabled, with three-quarters being listed as severely or profoundly retarded. About 90 per cent are dependent in personal care, and all but two have severe communications problems, many being completely unable to talk. The majority require 24-hour attendant care and approximately one-quarter have specialized nursing needs such as postural drainage, special feeding, intermittent catheterization and obsdrvation for seizures.

Now let us look at adults at Rideau Regional Centre, the large provincial facility for the developmentally disabled located in Smith's Falls, about 40 miles outside Ottawa. One hundred sixty-three adults from Ottawa-Carleton at this facility were listed as severely physically disabled in addition to developmentally disabled. Thirty per cent are under 25 years of age, 45 per cent from 25 to 34, 17 per cent from 35 to 44 and 8 per cent from 35 to 64. Ten per cent have been there five years or less, 11 per cent from 6-10 years, 34 per cent from 11 to 20 years and 45 per cent for more than 20 years. Only seven have been admitted within the past two years. Obviously, then, many have virtually grown up within the institution.

Judging by the brief assessments filled in by staff of the Centre, the vast majority appear to be quite severely affected, with a variety of sensory handicaps in addition to physical and mental disabilities. Only 22 are listed as independent in dressing, 26 in eating, 15 in grooming, and 32 in elimination, although over a third are reported as independent in mobility. Regarding communications ability, only 21 are listed as having no impairment, one is fluent in sign language, two are capable of simple sentences, 71 are capable of a few words or simple gestures and 58 are completely unable to talk. From this, it would appear that the large majority are very severely disabled with a group of approximately 20-30 with somewhat lesser disability.

Together, the multiply-handicapped children and adults from Ottawa-Carleton now residing in facilities outside the community form a large segment of the total severely physically disabled population and present probably the biggest challenge if the goal is eventual complete deinstitutionalization and repatriation to the home community.

Now let us look at the adult severely physically disabled in health institutions inside Ottawa-Carleton. Our enumeration here identified 243 persons aged between 18 and 65. Data were collected on 232. Of these 232 individuals, 130 are in chronic hospitals or chronic units of general hospitals, 40 in nursing homes or homes for the aged, 25 in rehab centres and 37 in acute hospitals awaiting placement. Fifty-six per cent are men and 44 per cent women.

Notice first the age distribution: only 30 per cent are under 45 years of age, 26 per cent are between 45 and 55, and 44 per cent are between 55 and 65. Regarding the primary disabling condition, multiple sclerosis and stroke are the two largest categories, accounting for slightly over one-fifth each. Head injuries are the third largest, making up 10 per cent. Other neurolocomotor conditions account for 7 per cent. Spinal cord injuries, tumours and cerebral palsy are the next biggest at 6 per cent each. The remainder are scattered over a wide variety of conditions.

Most are highly dependent in personal care, with over 40 per cent dependent on assistance from others with all five self-care activities and another one-quarter dependent in all but one activity. About seven per cent are listed as independent in all five basic self-care activities. Nurses were asked for their judgement of the patient's prognosis. Nine per cent were listed as improving, 66 per cent as stable at this time and 25 per cent as unstable or deteriorating.

Our measures of mental function were very crude, consisting of single item assessments by the nurse of mental awareness, cognitive functioning, emotional stability and comprehension. From these items a composite index was created dividing the sample into those with normal or near normal mental functioning, and those with significant impairment. By this measure, slightly over half were rated as normal, and half had a significant impairment in mental functioning.

Mental functioning was not closely related to age. Both young and old were almost equally divided between the two categories. The concentration of brain injuries among the younger patients is the main factor accounting for their rate of mental impairment. It should be noted that 21 patients were semi-conscious or comatose.

A subsample of 77 of the mentally alert patients in chronic hospitals, nursing homes and rehab were interviewed about their perceptions and preferences for future accommodation and care. Overall, 54 per cent stated that they would prefer to live in an alternative setting outside the institution if adequate services were available, 46 per cent that they would prefer to remain where they are. The most frequently chosen alternative was to return to their families, apartment living came second and group homes third.

There was a strong difference between those in nursing homes and those in chronic hospitals with the latter much more frequently opting to stay and the former seeking an alternative. There was also an age gradient, with the younger preferring alternative options and the older choosing to stay. Among those wanting an alternative, the older are more likely to wish to return to their families, the younger to live independently in their own apartments.

It was clear from the interviews that many of those who chose to remain would have opted for community alternatives if they could be really assured that adequate care were available. They found it hard to believe that this could be the case and were reluctant to even consider the possibility. This feeling is reflected also by their rejection of the option of a special unit within the institution where they would be grouped with their peers. They think they can get more privacy and care by sharing with elderly or unconscious patients rather than with their peers.

Aside from the interviewees' expressed preferences, we asked the nurses' judgement of the patients' ability to live in the community, assuming adequate support services and accommodation were available. This was asked for the whole sample of adults in chronic and extended care, not just the 77 people interviewed. The nurses estimated that 69 people or 40 per cent of those in chronic and extended care could live in the community if supports were available. Many care-givers emphatically stated, however, that this could only occur if funding levels were adequate to generate community support services and if assistance with integration were provided to reduce the trauma of change. We were unable to obtain similar care-givers' estimates of potential for community living for the multiply-handicapped in institutions outside Ottawa-Carleton.

This gives us a profile of the severely physically disabled and multiply-handicapped who now reside in institutions. The main point to note is that, in comparison with the situation ten years ago, many of the "easy" candidates for deinstitutionalization are now living in the community, and the remaining population poses more difficulties for rehabilitation. Among the multiply-handicapped, there is a preponderance of the severely and profoundly involved, many of who have spent years in this setting. Among the physically disabled in health facilities, a large proportion are older persons, those with wasting and unstable chronic diseases or those with brain degeneration or damage arising from their condition. This is not to deny that there are still many who obviously should not be there -- in the neighbourhood of 30-40 per cent in chronic and extended care -- or to downgrade the importance of alternatives for the others, but only to suggest that the remaining task will entail more intensive transitional programs, and heavier levels of community support care than in the past.

To summarize, in our surveys of the severely physically disabled and multiply-handicapped, we found a total of 478 individuals from Ottawa-Carleton in institutions. This represents an "institutionalization rate" of about 0.9 per 1,000 population under 65 in Ottawa-Carleton, and approximately one-third of our epidemiological estimate of all severely disabled in Ottawa-Carleton. The remainder are presumed to be living in the community. When we add the 72 in community projects, we get what can be termed an "out-of-home placement rate" of 1.06 per 1000 under 65 population. The ratio of those in institutions to those in community residential alternatives is now roughly 6.6 to 1.

The need for community residential places for those currently in institutions is just part of the overall demand, since there are also people in need of alternatives in the community. In the community surveys, our data were much less complete. For children and adolescents, our sample of 81 families was about half the estimated true proportion. About two-thirds were living with their natural families, one-third with foster parents. About 35 per cent were of normal intelligence, 35 per cent mild to moderately retarded, 30 per cent severely or profoundly retarded. They were quite dependent in functioning with almost three-quarters requiring assistance in three of more self-care activities. We concluded that almost 40 per cent of the children in the community were as severely physically and mentally impaired as the children surveyed in institutions.

The main immediate needs identified were relief care, increased financial assistance and help with the child's basic care. Although only two families were looking for an immediate placement, over half saw a need for alternative accommodation within 10 years. Of these about 32 per cent were estimated to need heavy 24-hour care, 43 per cent group homes and 25 per cent support apartment living.

Among adults, there were 260 respondents to the community survey but we estimated that this was only about 30 per cent of the true population. Of these, a relatively small number -- only nine -- saw a need for accommodation with support care right now, a larger proportion in five years (8 per cent definite, 36 per cent probable). Many, however, saw a need for increased and more flexible assistance with homemaking, attendant care and respite care.

There is a small group who need 24-hour, one-on-one attendant care to live in the community. There are two in Ottawa-Carleton right now. Like others in Ontario, they are caught in the Catch-22 situation where their applications for orders-in-council from the Ministry of Community and Social Services have been turned down because the type of care is labelled medical care.

In making our recommendations, our efforts fell short of what we would really have liked: precision and a specific plan for action. Despite our research, there were still big gaps in our information which made posing solutions uncertain. There is little in the literature, for instance, on the question of "medical fragility", and how you design cost-effective residential alternatives and care packages for groups such as the profoundly multiply-handicapped who need continuous nursing monitoring or the near-elderly with unstable, wasting diseases. We had no basis for estimating how realistic the option of returning to the family was for those who preferred it. Although we took it for granted that community care was more cost-effective than institutional care, for much of the target population, it would have been nice to have some hard data to convince policy-makers. It would also have been nice if there were some standards or guidelines for a complete system of community care and the full range of needed services for a given population base. For instance, although our focus was on accommodation and support care -- defined as basic nursing and attendant needs -- it is obvious that many of those who would be leaving institutions would need vocational services or day programs. We did not have the resources to do original research on this issue, nor could we find any ready-made guidelines to assist us in estimating accurately the need.

The study recommended a range of options so that choices would be possible. Overall, it advocated a substantial re-orientation of the system toward community care. Conservatively, it said there is a need now for about 120 new community residential places with a systematic further buildup over time. For in-home assistance, it recommended that the Ontario government implement the homemaker program announced two years ago, and, in the interim, that a pilot project be begun locally to provide attendant and homemaking services without the need for professional services. It also recommended that the Ministry of Community and Social Services and the Ministry of Health fund one-on-one attendant care for that small group who need it to live in the community. It recommended more small, normalized group homes to accommodate multiply-handicapped children and adolescents, both those now lodged outside Ottawa-Carleton and those needing placement from their families. It endorsed an existing proposal for a small group home for medically-fragile children to be operated by the Chilren's Hospital of Eastern Ontario.

Another high-priority recommendation was transitional living programs to help people make the adjustment from institutions and the family home to independent living. Among existing providers there was fear that many on their waiting lists were not ready for apartment and group home living. These programs would teach independent living skills like attendant management, financial management, consumer skills and social skills to ease a bottleneck in the existing system.

Now let us turn for a moment to the other two non-elderly disabled populations who are also in the market for community alternatives. We have already touched on the developmentally disabled who are severely physically handicapped. However, at Rideau Regional Centre there are another at least 200 severely and profoundly retarded individuals without severe physical disabilities from the Ottawa area. They are also candidates for deinstitutionalization and repatriation if these goals are to be pursued. In this total we should also include persons currently in other institutions besides Rideau Regional, including nursing homes and homes for special care. There are about 33 such persons in the Ottawa-Carleton area.

According to the 1984 workplan of the Ottawa-Carleton Advisory Committee on Services for the Developmentally Handicapped, there are currently 110 community residential places for the developmentally disabled. These include only eight core residential places for severely retarded children, 71 places in group homes for those with lesser disabilities, and 30 places in supported independent living apartments. In addition, the Ottawa District Association for the Mentally Retarded has about 70 verified names on its waiting list for residential services.

Among the psychiatrically disabled, the issue is apparently more the mix and location of placement than the absolute number of places. This is based on the results of another planning study recently completed by the District Health Council (1983) which used as the planning standard the "California Model" (Dubois, Elpers and Crowell, 1981). This model includes active treatment beds and concludes, by California standards, that we have a considerable surplus of these. The current stock of beds includes 229 in acute care, 35 in transitional care, 209 in long term care, and 411 places in domiciliary hostels, homes for special care and non-profit group homes (only about 40 places). These figures -- aside from acute care beds -- are not far off the California recommendations. However, all the long-term beds are located in Brockville, 70 miles outside Ottawa-Carleton, so the issue of repatriation applies here too. One may also question the heavy reliance on domiciliary boarding homes as the main community residential alternative. The District Health Council endorsed repatriation for those housed outside, but did not recommend building more long-term care beds here until the use of acute beds was examined. They did recommend the immediate creation of three more non-profit group homes of 10-15 places each. So, although the disparities do not look so great, they mask some very real problems concerning the creation of community alternatives for psychiatric patients.

One of the advantages of the California model used in the mental health plan was that it attempted to cover all elements in a more-or-less complete system, including the variety of community support services needed to facilitate social, vocational and recreation adaptation, and to specify standards for these services as well as for beds. In this respect, one of the biggest gaps between the present reality in Ottawa-Carleton and the model was in the area of community rehabilitation and case-management. On the basis of California standards, an immediate need for 47 case-managers was identified.

Bringing the three populations together, it is apparent that there is a long way to go toward complete deinstitutionalization. First, there are large gaps in the community services which would enable people to live at home, most notably, homemaking services, attendant care and respite care for the physically disabled, and case-manager services for the psychiatrically disabled. Second, there is a big shortfall in community residential places. For the severely physically disabled alone, there appears to be a deficit of at least 120 new community residential places based on very conservative assumptions about deinstitutionalizing the current institutional population. The ODAMR has a waiting list of 70 and this includes very few of the at least 200 people at Rideau Regional Centre. Although the need for community residential places seems less pressing for the chronically mentally ill population, this overlooks the out-of-community placement of over 200 people in Brockville and the fact that many of the existing community places leave a great deal to be desired.

This brings us to our first recommendation to the Canadian Council on Social Development. It would be a very useful exercise for someone to construct a national template for community planning which would set forth some guidelines for an ideal number and distribution of beds and community services for a given population base for the three main disability groups, along the lines of the California model outlined above. This would be based on the best epidemiological data available but would necessarily involve, initially at least, a fair amount of guesswork. It would also incorporate explicit value judgements about what alternatives are preferable. Such a model, arbitrary as it might be, would provide some focus for academic debate and refinement and, more important, it would give communities some targets to shoot for in planning a full range of community services for the disabled.

There is one obvious omission from the discussion up to this point and that is the situation of the disabled elderly. The prevalence of disability increases sharply with age, and most forecasts indicate that, with the aging of the population, providing services and facilities for the elderly disabled will be the biggest task of all. To complete the picture, there are approximately 2200 persons over 65 in extended and chronic care beds in Ottawa-Carleton for an institutionalization rate of about 4.3 per cent of those over 65. (This overlooks those occupying acute beds waiting placement.) There are also another approximately 900 in residential care and about 500 in domiciliary hostels. This yields a total out-of-home placement rate of about 7 per cent. The Ottawa-Carleton District Health Council (1980) estimated that, despite a rate of institutionalization that already exceeds the provincial average, and despite the expansion of community services to reduce this rate by one-third by 1990, 350 additional chronic and extended care beds are needed by 1986, and 520 more between 1986 and 1991, to meet the demand.

In its current pattern of institutionalization, how representative is Ottawa-Carleton of the nation as a whole? The best effort to examine the institutionalized population in Canada is that of Wilkins and Adams (1983), who, through a synthesis of Statistics Canada data, estimated that in 1978, the rate of long-term institutionalization for all ages for purposes of health care (including the developmentally disabled) was 9.1 per thousand. This rose from 1.7 of the 0-14 group to 2.4 of the 15-44, to 5.6 of the 45-64, to 16.9 in the 65-69 and so on up to 309.6 for the 85 plus. The rate for the 0-65 segment of the population is 2.9/1000, for the 65 + about 70.9/1000, very close to the totals for the various groups in Ottawa-Carleton. Wilkins and Adams' analysis indicates that in 1978 there were roughly 62,000 Canadians under 65 in institutions, and about 152,000 over 65 (3).

Wilkins and Adams (1983:115) estimate that, at present rates of institutionalization, the proportion of the Canadian population in long-term care institutions will almost double by 2031 simply on the basis of the changing age structure of the population (see also Woods Gordon, 1984). Manton (1983) has made a similar forecast for the United States, and has also estimated the formidable volume of formal and informal care which will be required to keep the remaining disabled elderly in the community. Despite the expansion of home care programs, some observers are not optimistic that the rate of institutionalization of the disabled elderly can be greatly reduced, given the increase in the fragile, very old group and the high incidence of senile dementia (Dunlop, 1980).

Discussion of the elderly brings into focus the need for clarification of the definition of an institution, of the sub-populations involved and their specific care needs, and the consequent issue of appropriate targets for reduction of institutionalization. Although large custodial institutions for the mentally retarded, mentally ill and physically disabled now look like dinosaura, consideration of the needs of the elderly, as well as certain categories of under-65 patients encountered in our surveys, indicate that some sort of long-term care settings offering professional medical and nursing care will continue to be required. Clearly, given the massive investment, we are going to have to build on, and try to improve, the existing system of long-term care to a certain extent. The task is twofold: making sure only people who **have** to be there **are** there; and improving the quality of life for those who remain.

A second research recommendation is offered, not necessarily to the CCSD study, but perhaps to the NRC Associate Committee on Research and Development in Rehabilitation of the Disabled. More work is needed, in conjunction with the development of a template for community services, on updating and expanding information on the present size and composition of the institutionalized population. This would serve as a baseline for evaluating future progress toward national goals. While first priority would go to identifying obviously misplaced groups, attention should also be focused on the groups labelled "medically fragile", "medically unstable", and "senile dementia" to determine what specific physical and mental states and care components are involved.

Caregivers' opinions from the three Ontario needs assessments are practically unanimous that 30 to 50 per cent of the under-65 physically disabled currently in chronic units and nursing homes could live in the community; but little is said about the remaining 50-70 per cent. What specifically makes them poor candidates for deinstitutionalization? In part, investigating this would appear to be a job for expert researchers and committees, but it is likely that the limits will only be discovered as they are tested by consumer and advocacy groups starting new projects. There is no self-evident technical reason why care cannot be provided in small homelike settings: the key issue is likely to be cost-effectiveness, especially if highly-paid health professionals must be involved.

This is the one area where cost-effectiveness studies seem to be warranted. There is little experience to date with community homes for the medically fragile. As projects of this type are started, their cost-effectiveness should be examined, perhaps in comparison to experimental normalizing units within larger institutions.

Regarding improving the quality of life in existing settings, the CCSD study could do a service by proposing a monitoring system, and disseminating information on successful changes. The paper by Bob Flynn to this conference suggests that the PASS instrument might be used in the former capacity. The addition of PASS principles to standards of quality assurance used by accrediting agencies would be one means of affecting monitoring.

Our next recommendation comes more to the point of the avowed purpose of this seminar, the topic of the best direction for cost-effectiveness studies. Using the example of Ottawa-Carleton again, when the needs of the three younger disability groups are taken together, and when those of the elderly are added in, the cost implications are disturbing. Nor, in our opinion, is it sensible to argue that there will be large offsetting costs savings from the closure of institutional beds. The literature and experience indicate that institutional costs have a remarkable persistence. It is probably realistic to ioncede that the costs of creating a community-based system are likely, in the short run anyway, to be mainly added on to the existing health and social service system costs. Given the present constraints on funding new programs, choosing among competing priorities **as the place to start** becomes very important. This is where tools of economic analysis would be useful.

Using the example of some issues which arose in our study, the following dilemmas come to mind. What priority should be assigned to repatriating and deinstitutionalizing the severely multiply-handicapped in institutions outside Ottawa-Carleton as opposed to concentrating on those with lesser disabilities? Within Ottawa-Carleton, how much attention should be paid to deinstitutionalizing the older patients as opposed to the younger? What is the viability of long-separated disabled being reintegrated into their families? Should the concentration be there, or should it be invested in non-family community residential alternatives? More broadly, what priority should be attached to preventing further institutionalization among those in the community as opposed to rehabilitating those in institutions who seem reconciled to this setting? If the former is given higher priority, and if home-based services are a major modality for accomplishing this, how can the selection process be refineu so that those at real risk of institutionalization receive priority? American studies suggest a large amount of real unmet need for homemaker services among the elderly and disabled which is likely to overload any program introduced unless careful selection procedures are followed (see Weissert et al, 1980).

There is also a whole set of issues concerning the relative priority of educational, vocational and recreation programs in the community as opposed to accommodation and support care alone. In our study, there were some serious undercurrents from disabled people themselves about the value of community living if the prospect of jobs or other meaningful activities was remote. Again, in a climate of scarce resources, the issue of how much money to spend on these programs, versus programs to deinstitutionalize increasingly broader strata of the institutional population, becomes an important one.

This almost ends the paper where it probably should have started, with the issue of appropriate methodologies for tackling some of these issues. Is it naive in the first place to think that cost-effectiveness analysis can really help to answer these questions? Probably not entirely so. As implied before, we don't think there is much to be gained by initiating massive new experimental studies of the cost-effectiveness of alternative options, with the one exception noted above. However, some useful perspective could be gained by various simulation and modelling studies which would use existing cost and effectiveness data to provide order-of-magnitude estimates of the relative value of different alternatives. The technique of cost-utility analysis (4) seems promising in this respect, since it reduces the effectiveness side to the common metric of quality-adjusted life years. The trick is obtaining the weights to do the quality adjustments, since present methods seem very narrow in this respect. However, ingenuity might provide some rough but practical working tools.

In closing, we are not advocating that these analyses ever become the sole basis of decision-making. Rather, they would become additional tools which would help inform decision-making. The ultimate goal must remain to provide a full and meaningful range of options for all disabled, and that goal is founded on human values, not economics. If properly used, however, these tools could assist us in defining interim priorities.

Notes

1. These include studies done in Metropolitan Toronto (Boston Gilbert Henry Associates, Levy Coughlin Partnership Inc., 1979), the Peterborough area, (Haliburton, Kawartha and Pine Ridge District Health Council (1983), and a study now under way by the Thames Valley District Health Council in London Ontario.

2. Readers are referred to the final report (Ottawa-Carleton Regional District Health Council, 1984) for details of the methodology, results and recommendations.

3. A supporting study to the Canadian Medical Association's Task Force on Health Care (Woods Gordon, 1984) has recently provided some estimates of the extent of institutionalization in Canada in 1981. Although the results are not strictly comparable to the Wilkins-Adams' study, they are quite close. According to this study, the overall rate of long-term institutionalization in 1981 was 9.2 per thousand with rates of 2.9/1000 for the 0-17 group, 2.3/1000 for the 18-44, 4.0/1000 for the 45-64 and 68.6/1000 for the 65+.

4. For an exposition of cost-utility analysis, see Torrance (1982) and other articles in the same volume. For critiques see Veit and Ware (1982), Llewellyn-Thomas et al (1984) and Avorn (1984).

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PART FOUR

WRAP-UP

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WRAP-UP AND LOOKING AHEAD

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It has been fascinating to sit here for the last two days, trying to figure out why I was chosen to summarize the presentations. I have decided that part of the reason is because I have an M.A., which should mean I'm not threatening either to Ph.Ds or those who do not have university degrees. I am also a consumer of services. I am and have been, at various times, a provider of services. I am a person who has been in an institution; I am now a person who is not in an institution. And I am also an advocate of both people who have been in institutions and who are now out of tiem. Those are all the things that I think are in my favour.

The things that are against me include that I come from Toronto, which means that everybody who comes from the east thinks I come from the west, and everybody who comes from the west thinks I come from the east, and everybody who comes from Ontario but not from Toronto thinks I come from Mars. I think my other negative factor is that I am heavily biased. I am not, as you might assume, a supporter of advocate groups for the physically handicapped (although I am not saying I wouldn't like to be). I am an Associate of the National Institute on Mental Retardation, because out of the parent advocate movement for people who are mentally handicapped has arisen the concept of normalization. Therefore, I am biased in favour of Dr. Flynn's paper. I take his comments as a fundamental structure of my comments; if you don't like what he said, you are not going to like what I will say.

First I bring before you the task. As I understand the task, the Working Group, and CCSD as one of the major partners, has to develop a new methodology for determining the cost-effectiveness of deinstitutionalization. I presume that this question arose out of the **Obstacles** report, which itself arose out of a panel that went across the country talking to people, many of whom were consumers of services that are supposed to be helpful to handicapped people. I am sure that what they actually heard was "For God's sake, can't you see that institutions cost too much? Can't you do something about it?" I am sure that that is what was actually said in the courtrooms and auditoriums across Canada. And somehow that has been metamorphosed into a question of finding out how much institutions cost. I don't suppose those people who reported to the Commission and ultimately wrote **Obstacles** really wanted anybody to find out how much institutions cost. I could be wrong, but I suspect that what they really meant was "How can we support and create competent communities; communities where people who are citizens can live?"

Of course, when you start off with the wrong questions, it is very hard to come up with the right answers. That reminds me of my last trip to Ottawa. It was the first time I ever drove around

Ottawa and people kept giving me directions. However, they gave me directions from places I wasn't at yet. I didn't stop being lost for two days. It wasn't until somebody finally started with where I really was that I was ever able to figure out where I wanted to go. And I think that is about where we are right now. I think that is what people have been saying for the last few days. Where are we? We have to figure that out before we can say where we really want to go.

Then, in answer to that question of, "Where are we?", a number of people (I cannot list all the names because it would take too long) mentioned that some very good statements about "where we are and where we would like to be" have already been written or established. For example, the World Health Organization has said that all of us in the world ought to be looking at full-citizenship participation. All people alive on the face of this world ought to be able to participate in their own community and in their own country. I believe that, and I think everbody around the table probably believes that. Some of us are not quite sure yet how some of our citizens can, or do, participate. But when we get to know some people who have been labelled psychiatrically disabled, some people who have been labelled mentally handicapped, or some people who have been labelled physically handicapped, we will find out that they can indeed participate, and they often already are participating, and what they want is a chance to participate more effectively. So the question is: "How can we make our communities more competent to receive the participation of all of their citizens?"

The next question is: "How much does it cost to re-create competence in the community?" We have to re-create competence or perhaps create it for the first time; I don't know for sure. But I do know that we have had big institutions, and big institutional thinking, for at least the last 150 years, and that has happened at tremendous cost to all of us. It has cost us our own competence in knowing how to deal with making everybody a participator. So, now we have to either create or re-create full competence in our communities.

How are we going to study that? How are we going to do that? People mentioned a number of paradigms that the Working Group can choose from. No matter what the group chooses, I believe we have to look to the individuals and the advocates who are already participating or who would like to participate. We have to talk to them. We have to help them. We have to participate, with those people, in figuring out what is best.

We talked about uniqueness of certain models and we talked about similarities. I think what we will find if we look across different communities and regions is that there are remarkable similarities among the models that work, with interesting and necessary peculiarities in certain details. Necessary, because no community wants to be precisely and exactly like Toronto or Ottawa or anywhere else. And when we think about it, and talk and work with individuals and advocates, we discover that they have already invented normalization or some other way of saying it with different words.

What we are talking about in normalization is full participation, presence in the community, individual dignity, a chance to grow and develop all through your life, living in circumstances that everybody else in the community would say are reasonable and decent circumstances to live in. Normalization is not very complicated, and it was created by consumers and parents and advocates. This is where PASS 3 comes in. Like Bob Flynn, I really like PASS 3. PASS 3 does in fact measure human dignity to a certain extent, as much as numbers can, and pretty adequately. One of the things that the Working Group can look at is the measurement of human dignity and participation, and PASS 3 could possibly be one way to do that. One of the things that Dr. Flynn's work tells us is that most of our programs, including 99 per cent of our institutional programs and even an awful lot of our community programs, do not offer human dignity and human participation to consumers. This brings up the point, which I think must be strongly emphasized, that there are a lot of institutionalized services masquerading as community services. These are just big institutions busted up into little pieces and spread all over the country.

We don't want to study the cost of the institution. We want to study the cost of total participation, of real community interaction. We want to look at the really good models that we already know about. All of us could send in at least one example of one good program. Jo Dickey's program is a good program. My program, where I live, which was the first in Ontario and probably the first in Canada to wrest individual funding out of the hands of a provincial government, is a good program. We could look at these to see if they come near the minimally acceptable level of human dignity on PASS 3, or on some other measure. Then we can say, "What is the cost of this?" Then, as more programs are started, we could start randomized experimentation if we wanted to. We could experiment between good community alternatives, finding out which one actually comes in with the best dollar. Let's not make people fight over indignities. Let's try to make them establish dignity with the least cost.

The last thing I would like to address is the marketing aspect. Has anybody ever seen the movie "The Right Stuff?" "The Right Stuff" is about how the United States decided to get into the space program, starting about the late '30s or early '40s, up to the end of the Apollo program. It is perfectly obvious to anybody who knows about that program that it cost an enormous amount of money, and nobody cared how much that program cost. Why? Because absolutely everybody in North America, and a great many people all over the rest of the wored, were sold on the idea of getting somebody into space. They had a dream, and a whole lot of people were sold on that dream. And when a whole lot of people are sold on a dream they don't think about money, they think about, "How can we do it?" Often, as nearly as I can tell, they pick the most expensive way, not the least expensive, because they really don't care -- they want to do it up in Gladwrap and do it the best they can. How do people get sold on dreams? Well, there is obviously more than one way.

The first thing we have to do is articulate our dream more clearly. There are a lot of people who do not know what the heck we are talking about. Even as we sit here in this room, although I think everybody in this room would say we don't need institutions anymore, we could not articulate it very clearly. How do you articulate dreams? You have to tell good stories. This is another reason for looking into the good models that we already have now. We should look into them with a view to telling them all over the world, so that everybody knows about our dream and the power that dream can have. Right now, the stories people hear about people who are impaired or handicapped are terrible stories. They hear terrible stories about 27 children murdered in the Hospital for Sick Children. They get terrible stories about Setpehn Dawson, presumably on his deathbed, dying from mental ratardation. By the way, I don't know if anybody has died from mental retardation -- what he was actually dying of was medical abuse. But that is not the story that people get out of their newspapers. They hear the story of somebody dying of mental retardation. Shouldn't we help him over the edge a little quicker? People hear terrible stories. How can we sell them on our dream if they think that everybody who lives in a wheelchair or has trouble learning to count is dying, and all that they need is to be helped over the edge a little faster?

Let us all say together that we should study what is good, and that we should help the people to make more of what is good, and we should participate with the consumers and the advocates because they have the energy to create what is good. Let us price what is good and, by all means, let's tell stories of what is good and spread our dream.

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